NATIONAL QUALITY FORUM

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PALLIATIVE AND END-OF-LIFE CARE STEERING COMMITTEE MEETING

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WEDNESDAY,
MAY 11, 2016

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The Steering Committee met at the National Quality Forum, 9th Floor Conference Room, 1030 15th Street, N.W., Washington, DC, at 8:15 a.m., R. Sean Morrison and Deborah Waldrop, Co-Chairs, presiding.

PRESENT:

R. SEAN MORRISON, MD, Co-Director, Patty and Jay Baker National Palliative Care Center; Director, National Palliative Care Research Center; Director, Hertzberg Palliative Care Institute, Icahn School of Medicine at Mount Sinai, Co-Chair
DEBORAH WALDROP, PhD, LMSW, ACSW, Professor, University of Buffalo, School of Social Work, Co-Chair
BOB ARCHULETA, MD, Physician, Pediatric Associates*
MARGIE ATKINSON, D. Min, BCC, Director, Pastoral Care, Ethics and Palliative Care, Morton Plant Mease/BayCare Health System
AMY J. BERMAN, BSN, Senior Program Officer, John A. Hartford Foundation
CLEANNE CASS, DO, FAAHPM, FAAFP, Director of Community Care and Education, Hospice of Dayton

MICHELLE CAUGHEY, MD, FACP, Associate Executive Director, The Permanente Medical Group, Kaiser Permanente
GEORGE HANDZO, BCC, CSSBB, Director, Health Services Research and Quality, Healthcare Chaplaincy
ARIF H. KAMAL, MD, MHS, FACP, FAAHPM, Physician Quality and Outcomes Officer, Duke Cancer Institute
ALICE LIND, Manager, Grants and Program Development, Health Care Authority*
RUTH MacINTOSH, RN, Continuum of Care Manager, Aetna
ALVIN MOSS, MD, FACP, FAAHPM, Director, Center for Health Ethics and Law, Professor of Medicine, Robert C. Byrd Health Sciences Center of West Virginia University
DOUGLAS NEE, Pharm D., MS, Clinical Pharmacist
LAURA PORTER, MD, Medical Advisor and Senior Patient Advocate, Colon Cancer Alliance
CINDI PURSLEY, RN, CHPN, Administrator, VNA Colorado Hospice and Palliative Care
AMY SANDERS, MD, MS, FAAN, Assistant Professor, Director of Cognitive and Behavioral Neurology, Departmental Quality Officer*
TRACY SCHROEPFER, PhD, MSW, Associate Professor of Social Work, University of Wisconsin, Madison, School of Social Work
LINDA SCHWIMMER, Attorney, Vice President, NJ Health Care Quality Institute
KARL STEINBERG, MD, CMD, Medical Director, Kindred Village Square Translational Care and Rehabilitation Center; Life Care Center of Vista; Carlsbad by the Sea Care Center; Hospice by the Sea
PAUL E. TATUM, MD, MSPH, CMD, FAAHPM, AGSF, Associate Professor of Clinical Family and Community Medicine, University of Missouri-Columbia School of Medicine
GREGG VANDEKIEFT, MD, MA, Medical Director for Palliative Care, Providence Health & Services

DEBRA WIEGAND, PhD, MBE, RN, CHPN, CCRN, FAHA, FPCN, FAAN, Associate Professor with Tenure, The University of Maryland School of Nursing

NQF STAFF:

KAREN JOHNSON, MS, Senior Director
ELISA MUNTHALI, MPH, Vice President, Quality Measurement
RACHEL ROILAND, Senior Project Manager
JEAN-LUC TILLY, Project Analyst
MARCIA WILSON, PhD, MBA, Senior Vice President, Quality Measurement

ALSO PRESENT:

REBECCA ANHANG PRICE, RAND Corporation
HEIDI BOSSLEY, Consultant to American Society of Clinical Oncology
DEBRA DEAN-WHITTAKER, Center for Medicare and Medicaid Services
TRACEY EVANS, American Society of Clinical Oncology
CRAIG JEFFRIES, Hospice Compassus
LAYLA PARAST, RAND Corporation*
STACIE SINCLAIR, Center to Advance Palliative Care
CAROL SPENCE, National Hospice and Palliative Care Organization

* present by teleconference

T-A-B-L-E O-F C-O-N-T-E-N-T-S

P-R-O-C-E-E-D-I-N-G-S

CHAIR WALDROP: Good morning, everybody, and welcome back. Welcome to our committee members. Welcome to our developers, and welcome to the NQF staff. And thanks for being here.

I think we'd like to go ahead and get started without any further ado, so I'd like to turn it over to Karen to make any comments about this morning.

MS. JOHNSON: Nothing major, just hello, good morning. Thanks for coming back after maybe a little bit difficult day yesterday. And, hopefully, we'll do more of the same good work today and maybe even get into some of the more fun discussions a little later.

I do want to talk to you guys about thinking about gaps in strategy going forward, so looking forward to our work today.

CHAIR WALDROP: Okay. So we have two groups of measures to consider today, and the first one is the group that we failed to get to yesterday afternoon. And I'm sort of thinking of that as the transitions in care measures. And I'm going to facilitate that discussion because Sean is on a number of those measures as a discussant. And then Sean will facilitate the CAHPS discussion. Oh, closer, sorry. And then Sean will facilitate the CAHPS discussion because I was on that as a discussant.

So I think we'd like to begin with 0211, which is proportion of patients who died from cancer with more than one emergency department visit in the last 30 days of life. And I would like to invite our ASCO colleagues to come and talk with us about the measure.

Good morning and thanks for being here. So I wondered if you could just give an overview of 0211.

DR. EVANS: Okay. Thanks. So, just to introduce myself, my name is Tracey Evans. I'm a thoracic medical oncologist at the University of Pennsylvania. I'm here representing the ASCO measure developers for these measures. I am a member of the Measures Task Force. I'm a volunteer for ASCO.

And I sort of wanted to give an introduction to the measures as a whole. So the next five measures are related. They are all related to the appropriate care of cancer patients at the end of life. And this is not the first time that they've been up for endorsement. They were initially endorsed back in 2009, and they were re-endorsed in 2012 -- bring up my notes here.

They were initially all process measures, but now we are putting forth three of them as intermediate outcomes measures. Three of them are used as ASCO's -- in ASCO's Quality Oncology Practice Initiative, which is an oncologist-led quality assessment reporting tool that oncologists use. Every six months, they audit their charts and report on these measures. The two that are not included in QOPI currently are actually going to be incorporated in QOPI for the fall of 2016.

So there is an opportunity when the audits are done for oncologists to complain if there are any unintended consequences with the measures. And, actually, none of these have had any red flags that have given us any concern for these.

These measures cite an ASCO provisional clinical opinion, which was put out when there was a flurry of literature showing an advantage to early palliative care in patients with advanced malignancies, and it was intended to give oncologists guidance for how to incorporate this information, and that early palliative care is a good thing for these patients.

All five of the measures have actually been proposed for MIPS or Merit-Based Incentive Payment System as part of MACRA. We have done any new testing on these measures because the criteria for approval has not changed as far as NQF, and they've already been up twice.

So I also have members -- none of us

actually were around when the development of these measures occurred in 2009, although we are the current stewards. So we also have ASCO staff here represented. Do you want to introduce yourselves?

MS. BOSSLEY: Sure. My name is Heidi Bossley. I'm consultant to ASCO. I've been in measure development for about 15 years now and, actually, used to sit at the front of the table and run the CDP. So I might look a little familiar to a few of you. But happy to answer any questions today.

DR. EVANS: So this is the first one that I guess we're going to address, the proportion of patients who died from cancer who had more than one emergency department visit in the last 30 days of life.

CHAIR WALDROP: Thank you very much. So I'm going to ask our discussants -- so that's Paul and Sean and Christine -- to take it away and talk to us about the evidence, please.

MEMBER RITCHIE: Great. So we're

going to divide this up. I'll talk about 2011, and Paul will talk about 2013. But, just as a backdrop, we had the opportunity to have a very robust discussion about this at our workgroup meeting, and so a lot of these comments are emanating from that previous conversation.

So, as a reminder, the measure title is proportion of patients who died from cancer with more than one ED visit in the last 30 days of life. And we'll first talk about validity -- excuse me -- evidence. And this was actually an interesting point of discussion because, if you look at the recommendation from the staff, the recommendation was that there was insufficient evidence.

And, in fact, when you look at the evidence that was provided by the developers, most of the evidence is by extrapolation. That is, that the question of how ED visits in the last 30 days of life influenced patient outcomes is one that one has to sort of make a few assumptions about, and it is not altogether clear that it is associated with better or worse outcomes. Unlike, actually, ICU data, which is much more clear about the relationship between ICU care in the last 30 days of life and patient and caregiver outcomes.

The data that's provided there is looking at a number of studies that show that, indeed, if certain kinds of models of care are followed such as home-based palliative care or a triage system within an oncology practice, that it can actually reduce ED visits. So there's this idea that perhaps ED visits are potentially avoidable, and that those avoidable ED visits then, theoretically, would be better for patients. And I don't think most of us would disagree with that.

And then there's, I think, as mentioned -- well, there was an ASCO sort of provisional clinical opinion in 2012, and then a Cochrane collaborative systematic review that looked at, again, models of care for patients with cancer and found that those who received, in this instance, home-based palliative care, had a decreased risk for dying in the hospital, but it didn't actually reduce number of ED visits.

Now, Dr. Kamal was gracious enough to remind us of a paper that, actually, I was involved in that looked at the CanCORS data, which was looking at cancer patients with either colorectal or lung cancer, and showed that, in that population, when they looked at both patient preferences and caregiver experience, that ICU care in the last 30 days of life was associated with worse outcomes and was less preference-aligned, that there was no relationship seen with ED visits. So that data, again, suggests some stronger relationships or evidence for ED -- excuse me -- for ICU care, but not so much for ED visits.

And so I'll stop there.

CHAIR WALDROP: Anything to add, Paul or Sean?

(No response.)

CHAIR WALDROP: Okay. Let me open it

to the committee for thoughts, comments, questions. I do want to check, are Alice and Bob with us on the line?

MEMBER ARCHULETA: Yes, this is Bob.

CHAIR WALDROP: Hi, welcome.

MEMBER LIND: Yes, this is Alice.

CHAIR WALDROP: Great, welcome.

MEMBER KAMAL: So I might mention two pieces of additional evidence. One, Deb Mayer did a really nice review of claims data from the State of North Carolina demonstrating -- and reflects what Brian -- Brian Hunis has studied it as well, which is about half of all ED visits by cancer patients happens during normal business hours.

So, from a cancer business perspective, we do think that that's an avoidable ED admission because we have infusion suites, you know, pretty much cancer centers, and even small practices should be set up to see those patients, even in an urgent-type basis. And that's what's been demonstrated by Brian's project at Memorial.

You know, in addition, if you look at why patients are seen in the ED, the number one reason, by far, during hours or after hours, is pain. And, you know, the oncology profession itself has called into question whether that is truly -- can be an anticipated and/or avoidable event. And so, now, this type of measure has translated to the Oncology Care Model, for example, so the leading alternative payment model for cancer put forward by CMS has very few quality measures in it, I think only nine or 10. But one of them is this measure, in terms of looking at sort of inappropriate utilization.

I think a measure like this has galvanized the field to think about what types of services it should offer. It calls into question what happens in under-resourced areas and more rural areas. And I have that question as well.

But, at the same time, calls into question if we're giving -- if we're giving toxic therapies to people, we should have the infrastructure to take care of them, especially during business hours.

CHAIR WALDROP: Thanks. Other comments?

MEMBER RITCHIE: So, just to follow up on Arif's point, which is another point that the work group discussed, which was what would be the potential unintended consequences of this measure. And one of the worries of the work group related to what Arif mentioned, which was the issue of access in rural settings where, essentially, by putting forward this measure, it could prevent people from getting the kind of access to care that they need that they might not otherwise have, especially if hospice is not readily available.

CHAIR WALDROP: Thanks. Other concerns or questions, comments? Arif?

MEMBER KAMAL: I might also put out, so Toby Campbell and Jim Cleary did a really nice study a couple of years ago looking at the University of Wisconsin experience, and really showed that the patients admitted to their oncology wards, by far the admission, you know, to being seen in the hospital in an unanticipated way was a predictor of death within six months. So I think that's a very cogent to this room, which is that that we also see as an avoidable piece of information.

The other thing from Deb Mayer's study shows that, of those seen in the ED, those like 1.7 million visits in her study in JCO, only eight percent of those patients were admitted, which means 92 percent were seen for something that did not require a hospitalization. So, if it's febrile neutropenia, it was low risk. If it was pain, that means they just needed a prescription, right. If it was anemia, they got a transfusion and left.

So it calls into question, can those 92 percent of people who don't actually need a hospital bed be treated in a different way, especially if half of them came between 8:00 and 5:00 when the oncologist is sitting in the office.

CHAIR WALDROP: Thank you.

MEMBER RITCHIE: Arif, it's really helpful to hear your inputs on this, so thank you. The one thing that I might also mention, and this is based on more anecdotal experience than evidence, is that, with the recent changes, both from the CDC guidelines around opiate therapy and increasing legislation at state levels for prevention of any ability to provide prescription opioid medications outside of a face-to-face visit, that actually also could potentially have significant impact if people are not given the opportunity to be seen wherever they are.

CHAIR WALDROP: Any other comments from the committee? George?

MEMBER NEE: Just, Christine, I mean I hear the rural argument, but is not the flip side of that that, if we have this measure and people are being seen in EDs because that's the only place -- I mean, we're not going to stop people from going to EDs because we pass this quality measure. They're going to still show up in their ED. But isn't the counter-argument to that that that then points up and -- you know, as Arif I think is signaling -- raises the issue of we need an alternative because look at all of these people who are showing up during business hours in our EDs.

MEMBER RITCHIE: That would be the ideal certainly, that we would have an alternative. The worry, I think, is that in situations where there's not access to any other urgent care situation other than the ED, especially in rural settings where often that that is the case, that those people could be potentially put in a place of higher levels of disparity.

CHAIR WALDROP: I want to keep us on the evidence, since that's really not about evidence, if I could -- that's okay. Paul?

MEMBER TATUM: I was just going to make the point, I think we went almost an hour on this particular metric, and I'm not sure that's going to move us forward on where the evidence ranks right now.

CHAIR WALDROP: I would like to ask a process question. I'd like to ask Karen to weigh in on the staff's suggestion of insufficient, and just ask if you can comment on that before we take a vote on evidence.

MS. JOHNSON: So, again, it felt like the evidence that was presented was a little tangential to the actual link that we were looking for. So, again, that's why we said insufficient. You guys, especially given some of the newer stuff that Arif has talked about, there might be more.

You know, I'll go ahead and raise it now. Often, ED visit kinds of measures are considered outcome measures, not intermediate outcome measures. And, if you look at it that way, the evidence bar is not as high, basically. NQF doesn't require as much evidence for outcome measures.

So, you know, I hesitate to bring that

up. The developer has brought this forward in the way that they feel like they should, but we have had questions about why is this an intermediate outcome and not an outcome measure.

CHAIR WALDROP: Would you care to comment on that?

MS. BOSSLEY: Yeah. So, as we as ASCO staff started looking at these measures, first agreed that these are not a process, and so felt that we needed to move it forward to an intermediate outcome. I don't think we're opposed to labeling these as outcome measures, but felt that we needed to kind of move in a judicious way from process to intermediate outcome.

CHAIR WALDROP: Okay. I just want to clarify one more thing before we vote, and that is to ask Karen -- or just to clarify that we, yesterday, got a little bit confused about insufficient with exception. And I just wanted to ask Karen to comment on is this a possible -- if we were to vote as this insufficient, could we call it an exception?

MS. JOHNSON: Yes. So it would work just like yesterday. If you feel that the evidence is not there, then it's insufficient. Then we would need a majority, more than 60 percent of you, to vote insufficient. And then, if you have the appetite for it, to go ahead and invoke the evidence exception. So it would work exactly like yesterday.

CHAIR WALDROP: Thank you. So are we ready to vote on the evidence?

(No response.)

CHAIR WALDROP: Seeing no objections, I'm going to ask Jean-Luc to let us know when we're ready to go.

MR. TILLY: Sure. We're ready right now to vote on evidence for 0211. Please go ahead and select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient.

MEMBER BERMAN: Reminder, I'm a recusal.

CHAIR WALDROP: Thank you for

reminding me. I'm sorry that I didn't mention that at first.

MR. TILLY: I'm sorry. We just need a couple more in the room. Okay. The votes are one voting for high, four voting for moderate, one voting for low, and 16 voting for insufficient. So the measure receives an insufficient on the evidence.

CHAIR WALDROP: So then we would next move to voting on whether we choose to make it insufficient evidence with exception or no exception.

MR. TILLY: That's exactly right. Select 1 for insufficient evidence with exception. Select 2 for no exception.

I'm sorry. We are looking for just one more in the room.

So the results are 21 voting insufficient evidence with exception, one voting no exception. So the result is the measure passes evidence with exception.

CHAIR WALDROP: Great, thank you. So

we'll move on to considering opportunities for improvement and gaps. Christine?

MEMBER RITCHIE: So our measure developers provide two different sets of data from two different integrated health systems and certainly demonstrate meaningful performance gaps from both systems. They collect the data, it looks like, a little bit differently. And then the other study that was described earlier also showed disparities in terms of ED utilization.

CHAIR WALDROP: Thanks. Anything to add, Paul or Sean?

(No response.)

CHAIR WALDROP: Any comments from the committee?

(No response.)

CHAIR WALDROP: And I should ask, anything from Bob or Alice?

(No response.)

CHAIR WALDROP: So no comments on gaps or opportunities for improvement. Okay. Jean-Luc, are we ready to vote?

MR. TILLY: To vote on performance gap for 0211, select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient.

The results are five voting high, 16 voting moderate, zero voting low, and one voting insufficient, so the measure passes performance gap.

CHAIR WALDROP: Thank you. Okay. So we'll move into looking at the scientific acceptability of the measure properties, and we'll start with reliability, so looking at specifications in reliability testing. Christine?

MEMBER RITCHIE: So there was no update to the reliability testing from the previous time that the measure was provided. However, there were two different ways that the testing has been done in the past, one, looking at a particular practice, which I'll describe more in greater detail when we get to validity, and then also with the registry.

And I think this is where the work

group started having some challenges, especially around the identification of people who had died for the purpose of measurement. So, in a registry setting, certainly one would be able to theoretically identify those individuals who were decedents, in claims data not so much. And so that ends up being a tricky dynamic with respect to this particular measure.

For the claims data, the developer states that the measure is 89 percent accurate, percent true positives and true negatives.

CHAIR WALDROP: I think it just would be helpful if we addressed the staff's recommendation of insufficient, just so that we're clear on what the thinking about that is now. And I'm wondering, Sean, do you want to take that?

CHAIR MORRISON: I just actually had a question for the developers because death data is almost impossible to get through claims, and it was unclear to us where the denominator population was coming from.

MS. BOSSLEY: Sure. So the denominator population is actually from death registries, not from claims. So that -- it's a combination of claims for the numerator, and then the death registry for the denominator. Does that answer your question?

CHAIR MORRISON: The other question was, how are you going to deal with MA plans and non-Medicare or other -- or the non-Medicare population, or the MA plans?

MS. BOSSLEY: So I think one thing that will help is moving this into QOPI because it will be broader. It will be practice-based. Beyond that, it's a challenge. I don't think that we have an answer for that.

CHAIR WALDROP: Karen, would you want to comment on the insufficient recommendation from the staff?

MS. JOHNSON: Sure. Sorry, I just took a bite. Sorry.

I think really the main question was what was going on with the claims data in terms of the death registry. So I think the insufficient was related to not having clarity about that in the specifications, as well as not having any testing for that piece of the measure.

So it would be up to you to decide if you feel like that you don't have to do, you know, checking of death registry data. Kind of like we talked about yesterday, if you identify your case from claims, you know, sometimes people will just look at -- if you're doing inter-rater reliability, they'll just look at the numerator piece and not worry about the denominator. And, if that's how you're looking at things, then that would be fine.

I think the main thing is to have clarity about the death registry. That was the big question.

CHAIR WALDROP: Okay. I think we're ready to vote on reliability.

MEMBER RITCHIE: Can I just ask the developers a question?

CHAIR WALDROP: Oh, I'm sorry. Go

ahead, Michelle. Two questions. I was too hasty. Sorry.

MEMBER RITCHIE: So, just as a question, do you have any updated reliability data around how your registry is performing relative to other kinds of chart instruction strategies or that sort of thing that you could bring to bear here?

MS. BOSSLEY: So I think, in this measure specifically, no, because it has not been implemented in QOPI. If you look at the other measures, there are five in total. Three are used in QOPI. That might give you -- that information from that might give you a sense of how this measure might perform but, unfortunately, that would be all we could provide at the moment. I don't know if that helps, but --

CHAIR WALDROP: Michelle?

MEMBER CAUGHEY: Thanks. How did your subcommittee -- where did you come down? What was your discussion in your small group?

MEMBER RITCHIE: Go ahead, Sean.

CHAIR MORRISON: It doesn't matter. We came down on insufficient pending whether -- asked the developers could come back and clarify where they were going to get the denominator files from. I think we all felt that if they were coming back with registries we would probably be fine with it.

I think, you know, my comment of the other plans, every measure that uses mortality in the CMS program now has run into the same issues, so I wouldn't hold this to that -- I wouldn't hold that to that standard because everybody is wrestling with the MA plans and commercials.

CHAIR WALDROP: Paul?

MEMBER TATUM: So, from a process piece, there's a manner to somewhat table this and see what this looks like in the other measures in terms of how you respond to the mortality.

CHAIR WALDROP: But they didn't actually do reliability testing on this measure.

MEMBER TATUM: Right.

CHAIR WALDROP: Because they didn't -- because it wasn't put into QOPI. Am I misunderstanding?

MEMBER RITCHIE: To answer your question, so this -- part of why we didn't do additional testing is this had passed on reliability in the past, and are we supposed to be reevaluating on those metrics that it had passed in the past that haven't changed?

MS. JOHNSON: So that's true as long as you continue to meet the current criteria. So our criteria are saying -- say that you, for everything -- we need testing for the metrics specified. So you have specified for registry. You have specified for claims. So we need to see testing for both of those.

MEMBER RITCHIE: Right. They are the same as they've been, though.

CHAIR MORRISON: Welcome to scientific peer review process.

MEMBER RITCHIE: Okay.

CHAIR MORRISON: We will not apologize for the fact that the prior committee may have missed this, which we did not sit on.

CHAIR WALDROP: Arif?

MEMBER KAMAL: I mean, as has been said, tumor registries are very highly specific and sensitive methodologies. They're just generally six months behind, but they're very good. The evidence that's provided here from, I think, Deb Schrag's group was a cooperation between Dana Farber and Blue Cross Blue Shield, and was under the auspices of a research project. So there was sort of additional efforts provided to get that data, you know, sort of ahead of the six-month period of time.

So, you know, this is unique data but the ability to arrive at these conclusions, I think, is similar, just probably delayed in a normal abstraction period of time, because we have to do this. Every cancer center has to report this data, has to know the mortality. We just end up knowing it six months down the road, not in time for, you know, this kind of publication.

CHAIR WALDROP: Two more. Christine?

MEMBER RITCHIE: I think, to your question, I think one of the things that's happening is that the world is changing profoundly around claims. I mean, now a third of the Medicare beneficiary population is under Medicare Advantage. That's never been the case before.

And so what our reality looks like now with respect to claims data is profoundly different than it was even five years ago.

CHAIR WALDROP: Any other comments before we vote on reliability? Jean-Luc?

MR. TILLY: To vote on reliability for 0211, select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient.

And the results are 10 -- are zero voting high, 10 voting moderate, two voting low, and 10 voting insufficient. The measure is in the gray zone.

CHAIR WALDROP: Okay. Moving on to validity testing and threats to validity.

MEMBER RITCHIE: So we sort of covered some of this already, and that is -- and Arif mentioned this earlier. In terms of sort of the two different ways that validity testing was assessed, one was based on claims data that sounds like was connected to the registry for this population of 150 patients at Dana Farber.

Just in terms of what was available, it looked like the numerator data elements were compared but not the denominator data element, although I think, now that you've told us that that was related to the registry, we can assume that the denominator data element actually had a robust way of assessing mortality.

And then, with respect to face validity, the developer stated that face validity was assessed. There was some focus groups conducted and then vetted by an expert panel of cancer patients. The challenge was we just didn't have a lot of information, and our understanding from what NQF requires is that they require a little bit more detail around face validity testing.

The threats to validity related to also risk adjustment and a wondering if, again, with respect to other risk factors for EDs, whether or not risk adjustment shouldn't be considered.

CHAIR WALDROP: Paul and Sean, anything to add?

MEMBER TATUM: That was a robust topic of conversation about risk adjustment, and think our working group felt probably yes.

MEMBER MORRISON: I think I was one of the strongest proponents that this measure -- the time had come for risk adjustment, that there -- when you think about the unintended consequences of vulnerable patients who need to be protected, who (a) live in settings where hospice is not yet available, (b) in the inner cities, and (c) because this is a measure that applies to group practices and clinicians and not to GRG-exempt cancer hospitals, the easy way to avoid this measure is to tell your patient at home, don't go to the ED.

It's patients often call their doctor and say, what should I do. And, if they say, go to the ED or stay at home and I'll take care of it in the morning, I just think without appropriate risk adjustment in this measure, I'm very concerned about seeing it moving in -- I'm very much concerned about it moving forward. And I think risk adjustment is possible. There are data that are available to risk-adjust.

CHAIR WALDROP: Other questions or comments?

(No response.)

CHAIR WALDROP: Are we ready to vote on validity?

(No response.)

MR. TILLY: So, again, this one is a little bit different. Since face validity only was conducted, you have just three options, 1 for moderate, 2 for low, and 3 for insufficient.

And the results are six voting moderate, five voting low, 11 voting insufficient. So the measure does not pass validity.

MS. JOHNSON: Hang on just a second and let me -- it's 11 out of 22, Jean-Luc? No, it's six out of 22. Okay.

We have a -- sorry -- that make this one feel just a little bit different to me, and I'd like to have a little bit more information about why you landed on insufficient. The reason that I say that is -- well, let me stop there. Was it the testing mostly or was it the risk adjustment? That's my question here.

CHAIR WALDROP: Christine?

MEMBER RITCHIE: I can't speak for the group here, but I can say, with respect to the work group, our biggest worry was around risk adjustment.

CHAIR WALDROP: Paul?

MEMBER TATUM: I actually think there was a comment where there was some consensus that, if we had risk adjustment, we agreed we'd move the subcommittee tomorrow.

CHAIR WALDROP: Anyone else care to weigh in on their vote on insufficient? Amy?

MEMBER SANDERS: So I was not in the work group, but I was swayed by the risk adjustment argument.

CHAIR WALDROP: Thanks. Is that enough to go on, Karen?

MS. JOHNSON: Yeah. And Elisa and I are -- yeah, Elisa and I are talking about options. We actually have an option that might be palatable to you guys, and it may not be. So let me put it on the table. That option is something that we call deferral, okay, so deferral of endorsement.

If we go that route, again, not something that we would do often, we would have -- and I'm pulling up our policy right now. Basically, the idea is, if it's a risk adjustment question and if the developer is thinking that risk adjustment is the way that you would be proceeding, which is not completely for sure, right. We don't know that yet.

Our option might be to defer your endorsement decision for a limited amount of time, something on the order of six months to maybe 12 months, but not years, to allow the developer to come back with a risk adjustment approach.

So maybe we should start with the developer, see what you -- see if that's even of interest to you, and then we'll talk about it as a committee.

DR. EVANS: So I'll start and, Heidi, feel free to fill in.

So risk adjustment is not something we've done with the QOPI metrics because they've been practice-specific and meant to compare practices to themselves and give them an opportunity to improve. None of these are meant to be zero numbers. We weren't meant to have people never come to the ED. But, certainly, I think, for patients with advanced cancer who are within 30 days of death, multiple ED visits is a bad thing and not the optimal way to take care of these patients. And capturing that is important.

Now risk adjustment for all of our metrics is something that we have been considering and are willing to take on, so that is certainly something that we could do.

MS. BOSSLEY: Yeah. So I think, as we looked back as staff, not having been a part of the development of these measures, thought the same thing, that perhaps risk adjustment needs to be at least examined, particularly with the sociodemographic variables, which I think is what all of you have been talking about. Those are the things that we have wrestled with as well.

And, now that you allow that, ASCO would welcome, I think, the opportunity to try to get this done. I don't know how long it would take, but it was -- what you have said around this table is exactly what has been discussed by ASCO.

CHAIR WALDROP: Sean?

CHAIR MORRISON: That would be terrific. I mean, I think we are in a very brave new world compared to when these measures first went in. And, if we're really looking at these for accountability rather than just practice improvement, and given the known variation we see related to sociodemographic factors, which are well beyond sometimes many oncologists' control, I just think that this particular measure needs risk adjustment.

CHAIR WALDROP: Arif?

MEMBER KAMAL: So, you know, oncology is facing this unique dilemma, which is which parts do we risk-adjust and which parts do we just say are standardized across the board, sort of reduce these events for all populations. You know, and so if you imagine -- you know, it's trending towards -- like bone marrow transplants centers are accredited and have specific, you know, guidelines of what they're supposed to be doing in terms of outcomes. And bone marrow transplant centers are not risk-adjusted, right?

If you say you have one, then you must do what people do in Manhattan, in Utah, et cetera. It doesn't matter.

And oncology is moving towards but is not there yet this idea that, if you are going to put toxic things in people and take care of their cancer and the experience with cancer, then there are a minimum set of things that you need to provide and things to avoid. And this is increasingly becoming one of those sort of mandatory things that cancer centers should pay attention to.

But I agree it's not there. So one could use the measure to sort of bring that standard up to bear and say, you know, maybe there are certain things we shouldn't take into consideration. Maybe we use risk adjustment as a way to get there. You know, I'm not sure.

The other thing that might be helpful for ASCO to hear from this group is on what specific -- other than demographics -- should we be risk-adjusting on, because it sounds like, in addition to the patient population, we should think about the environment, the neighborhood, and potentially even the characteristics of the cancer center itself, right.

So one of the ASCO programs, you know, is looking at underserved populations. There are cancer centers that have two oncologists in Harlem, right. And so, you know, if you risk-adjust on the density of ERs, there's a high density, right? If you risk-adjust on -- so the question is what would one risk-adjust on for that population.

CHAIR MORRISON: I'm going to -- Deb asked me to put my chair's hat on. I think I want to warn us that our roll is not to redefine, respecify, or do the scientific process for the risk adjustment for them. I think we can say that we'd like to see that, but I'm afraid that we can't give advice as to what would be the parameters. That's up to the measure developers. We can evaluate that when it comes back.

Sorry, my friend.

CHAIR WALDROP: Cleanne and then Paul.

MEMBER CASS: I just can't keep myself from saying that this measure has brought about some huge clinical good outcomes and improved outcomes in our community, that patients would have had a horrific death if not for being seen by their oncologist rather than an ED doc in the final days of living and getting segued over to the hospice unit, as opposed to being admitted to an ICU, where families were totally not expecting it and were not on board. But, because the oncologist sent them to us, we were able to effect a very good, comfortable death. So thank you.

CHAIR WALDROP: Paul?

MEMBER TATUM: A quick comment and then a process question.

The comment is, we also have to think about the very, very rural small town family physician on this measure in a county that doesn't have access to hospice, is far away from a cancer center, as we think about this measure.

The process question is I'm sensing some relief because many of these feel we need these measures desperately, and some relief that there's a way to move forward. And I wonder what our processes to move to deferment at this point, hearing some general consensus, is it a good thing. Is that a motion? What's the mechanism to --

CHAIR WALDROP: My question, too, so I'm going to ask Karen and Elisa if you can please help us out here.

MS. JOHNSON: We don't actually need motions. It sounds like the developer is willing to do that. It sounds like many of you on the committee would like to see that. So we don't have to be formal about this.

Where we will be formal is we have to come to some kind of timeline that we agree to. And I'll read our policy. The steward developer must confirm the feasibility of the changes, agree to the timeline, and follow up with our staff. So we will be doing this. Within 14 days, we'll be asking for a plan of how that would go forward.

I will say, in terms of risk adjustment, you know, we are in a trial, what we're calling our SDS trial, and you would probably be pulling this in after the end of our trial. The nice thing about the work that's going on in that effort is we're starting to understand a little bit better some of the data sources, some of the things to think about, so you can actually kind of maybe use some of the work and information that other developers are looking at as they're thinking about the risk adjustment for SDS as well as other factors.

I think the other thing that you'll really have to -- the rule idea has come up in some of Arif's ideas. The methods are -- it's still a little iffy about which things you should be adjusting for and which you shouldn't. So you will have some -- it'll be a substantial lift to do this work.

Because all of those questions haven't

been answered yet as to what is really appropriate to include in case mix adjustment and maybe which aren't.

So I guess, developers, are you willing to follow up with us within 14 days? We would need a timeline. Elisa, do -- I'm thinking a 12-month timeline. We could potentially go a little bit longer, or do we want to do a 12-month?

MS. BOSSLEY: If you will give us 14 days to do our homework, if that's okay, and then we'll come back.

MS. JOHNSON: Okay.

MS. BOSSLEY: But it will not be six months. It's 12 months for sure, I think.

MS. JOHNSON: Okay. And, with that, we will discontinue any further discussion on this measure and go to the next.

CHAIR WALDROP: Okay. Thank you. Thank you for clarifying the process, Karen.

So we will move on to measure 0213, proportion of patients who died from cancer admitted to the ICU in the last 30 days of life. And I'll ask our developer colleagues if you have anything further you want to add about this measure.

DR. EVANS: No, only that we may run into some of the same issues.

MEMBER TATUM: And I will ask for my colleagues to help on some of the methodologic issues as we move, because there probably are some differences. And Sean and Christine will help on that.

So we're looking at measure 0213. This is the proportion of patients who died from cancer who were admitted to the ICU in the last 30 days of life. And I cut in. Did you guys have any other comments you wanted to add on that?

DR. EVANS: We're okay.

MEMBER TATUM: So this looks at proportion of patients who died from cancer admitted into the ICU in the last 30 days. We have at the evidence level -- and, again, our numerator being dying from cancer and in the ICU in the last 30 days, and the denominator being deaths from cancer.

It was put in as an intermediate clinical outcome. And, as a reminder, this is a maintenance of endorsement.

Our first task on the evidence are our final recommendation from the team initially was evidence is low. But I think I can make a case that we could bump this up to moderate. And the issue from the first review was, can we state that there's a high degree of certainty that the benefits clearly outweigh some undesirable effects. And I think, with some of the additional research that Arif and Christine talked about on the last evidence piece, the patient and family issues there really will move it forward.

They have similar -- prior review had a retrospective covert study. There's consensus statement data. The update included a Cochrane systematic review, which looked at cancer patient in home-based palliative care services and found increased chance of dying at home and reduced symptom burden. A little bit indirect, not ICU metrics. But, if you're dying at home, you're not necessarily in the ICU.

Clinical opinion from ASCO also putting a number of studies that have evidence of benefit and, while not systemic review, the clinical opinion piece there as well.

And a number of articles that link to reduced ICU visits, meeting and matching up with patient outcomes.

The new study that Christine had referenced earlier which was 1,146 family members, Medicare patients, advanced lung and colorectal cancer, in the Cancer Care Outcomes Research Surveillance study, they looked at family members of patients who were admitted to the ICU within 30 days. And, in this group, family members reported excellent end-of-life care far less often, if they had that ICU admission.

So I think that can bump us up to the moderate piece on the evidence.

CHAIR WALDROP: Thank you. Anything to add, Christine or Sean?

(No response.)

CHAIR WALDROP: Okay. Any comments from the group on the evidence or questions about the evidence? Sorry.

Okay. No questions or comments on the evidence?

(No response.)

CHAIR WALDROP: Okay. Then I guess we'll move on to voting on the evidence. Jean-Luc?

MR. TILLY: All right. To vote on evidence for 0213, select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient.

The results are two voting high and 20 voting moderate, zero voting low and zero voting insufficient. Measure passes evidence.

CHAIR WALDROP: Okay. Thank you. So we'll move on to consider gaps in care, opportunities for improvement, and any issues with disparities.

MEMBER TATUM: Gaps and the opportunities for improvement are listed before you. You see that there is data from two integrated healthcare systems. It looks at the QOPI, which we've heard about registry. And you can see a fairly wide variance in the numbers. And then, if you'll look at the minimum and maximum of two years in the second IHS data set, I think we can make a pretty legitimate case there for the gap.

We could also reference the Dartmouth Atlas work which talks about why regional variation is another thought process. And I think this would be consistent with the recommendation of a moderate.

CHAIR WALDROP: Thank you. Anything to add, Christine or Sean?

(No response.)

CHAIR WALDROP: Okay. Any comments or questions from the committee?

(No response.)

CHAIR WALDROP: Anything from Bob or Alice? I just want to make sure to include you. Since we can't see you, we want you to know we know you're there.

MEMBER LIND: Nothing, thank you.

CHAIR WALDROP: Did you -- okay. We'll move to voting on opportunities for improvement.

MR. TILLY: All right. To vote on performance gap for 0213 select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient.

The results are three voting high, 18 moderate, one low, and zero insufficient. The measure passes performance gap.

CHAIR WALDROP: Thank you. So we'll go on to consider the scientific acceptability of measured properties. And we'll start with reliability, looking at the specifications and testing for reliability.

MEMBER TATUM: This is somewhat similar to where we were on the previous discussion. This data comes from administration claims as well as registry. Our big topic of discussion was how we get to the death data piece on the registry.

Data element validity being demonstrated as, I suppose, a fair degree of challenge. The questions were how well claims could identify cancer deaths. And, if we can easily show the claim status given to cancer deaths, we run into some challenges -- I'm sorry -- with the registries, that gets us to the moderate rating.

And, Christine, you had some other thoughts on how we hit that aspect for this measure?

MEMBER RITCHIE: I think you've already provided some clarity. I think the question we just had was how closely connected the data was to the registry data. It sounds like it emanated from registry data, and we are more confident about registry data numerators and denominators than we were around claims data.

CHAIR WALDROP: Any other comments or questions? Woody?

MEMBER MOSS: I'm in the subgroup and I evaluate this. Do you recommend insufficient or moderate?

CHAIR MORRISON: We recommended insufficient until the developers came back and gave us the data. It just wasn't clear in the work group. So I think that was where we were, Woody.

CHAIR WALDROP: Any other questions or comments before we vote on reliability?

(No response.)

CHAIR WALDROP: Seeing none --

MR. TILLY: This one is a little bit different. Since we only looked at data element reliability, your options are 1 for moderate, 2 for low, and 3 for insufficient.

And the results are 14 voting moderate, one voting low, and seven voting insufficient. The measure passes reliability.

CHAIR WALDROP: Okay. We'll move on

to considering validity, validity testing, and threats to validity. Paul?

MEMBER TATUM: So validity testing was done with administrative claims issues looking from Dana Farber, the comparison to data from the full medical record. The second was face validity assessment by focus groups and structured interviews within the life of care patients -- caregivers, expert panels. The testing of administrative data has a fair sensitivity and specificity measures.

It felt that there was accuracy in being able to identify an ICU stay within 30 days of death. And I think, from a standpoint of face validity, there was no new assessment. I think one of our big issues was it felt like there was far less risk of a potential hidden harms with this measure compared to the ER measure. So we felt, in general, there is still some of the, I guess, potential questions, too, about differences, but we were able to reach a benchmark of less than four percent in the SEER regions.

I think our sense was we were close to really meeting validity on this measure compared to the ER measure.

CHAIR WALDROP: Any other comments from Sean or Christine?

CHAIR MORRISON: And this comes back to Dr. Kamal's issue. I think the group, in contrast to the ED measure, this was -- the denominator here is people who die hospital deaths, so -- ICU deaths. And we felt that holding a hospital system or hospital accountable was -- set the bar a little bit higher than holding an individual practitioner in a community responsible.

And, although we would have liked to see risk adjustment, we were much more comfortable without it on this measure, given what the denominator was.

CHAIR WALDROP: Thank you.

MS. JOHNSON: I do have a couple of clarifying -- or, really, just one clarifying question for the developer. Is this a facility-level measure, or is this still a clinician practice measure?

MS. BOSSLEY: So all of the measures before you are practice.

CHAIR MORRISON: I think, given the fact that the numerator is ICU deaths rather, not hospital deaths, we actually felt pretty comfortable that, even if somebody was admitted to the hospital, the cancer center had control over whether they died in the ICU in that hospital or not. So we were less worried about the risk adjustment.

CHAIR WALDROP: Arif and then Gregg.

MEMBER KAMAL: Yeah. So I'm just making sure we -- so it's ICU stay, right, within 30 days of death? So agnostic as to where they die. But I agree with the point. No, but I agree with the point. The point is the hospital has control over that.

I'm actually reassured. And I brought this up on the work group call about the issue of, you know, what is an ICU and so on and so forth. But the really high sensitivity between claims data and medical abstraction data is reassuring to me because you can be on unit 9200, which is oftentimes beds are flexed to an ICU. So an abstractor might say that patient was in the ICU or in an ICU level of care, where the claims says the opposite or either way.

So it's reassuring to me that there is agreement between how people are billing the stay and what's being recorded in the chart, that people aren't getting confused by the geographic location of service, of what was that bed on that day considered ICU or not. And that's reassuring to me.

CHAIR WALDROP: Gregg, did you have --

MEMBER VANDEKIEFT: No, Arif asked the same question. ICU stay is not deaths.

CHAIR WALDROP: Thanks for the clarification, everybody. That's helpful.

Are we ready to consider voting on validity for this measure?

(No response.)

CHAIR WALDROP: It looks like it.

MR. TILLY: Okay. The polling is now open for a validity testing vote. Again, it's a little bit different, so just vote 1 for moderate, 2 for low, and 3 for insufficient.

Okay. The results are 20 voting moderate, one voting low, one voting insufficient. The measure passes validity.

CHAIR WALDROP: Thank you. Karen has a question for us.

MS. JOHNSON: Sorry, Sean. You're not the only one that thinks it's a little early this morning.

As we write the report, I want to make sure that I get it right. So can you guys give me the link again. The testing was for claims, not for registry, but you're okay with registry. So can you just connect those dots for me so that I can write in our report why you didn't need to see testing for the registry? I'd appreciate it. Thank you.

MEMBER TATUM: Sean, you may have better expertise at answering that than myself.

CHAIR MORRISON: I'm sorry, Karen. Can you repeat the question?

MS. JOHNSON: Yes. So the measure is specified for both claims and the registry, but there was no testing for registry. Face validity may have accounted for that, but there wasn't enough information to know if it really meets NQF requirements for face validity.

So what we have here is either not enough information to go with the face validity or no testing for registry. But I thought I heard you guys say that you're okay with no testing for registry.

CHAIR MORRISON: Yeah. I think what you're --

MS. JOHNSON: And I just need --

CHAIR MORRISON: I think what you're hearing from us is comfort based upon the existing data there on the accuracy of registry data for these elements, is what --

MS. JOHNSON: Okay, so kind of general knowledge that --

CHAIR MORRISON: Face validity.

MS. JOHNSON: -- face validity of the committee that registry elements typically are accurate.

CHAIR MORRISON: That is correct. And SEER, for example, is a very accurate registry.

MS. JOHNSON: Okay. Great.

CHAIR MORRISON: And not to have to completely test what's a known valid source over and over and over again is, I think, what you're hearing.

MS. JOHNSON: Okay. And, even though these data are not captured in SEER, right? This is -- I'm sorry to be so dense. I just --

CHAIR MORRISON: I'm sorry. No, I used -- yeah, I used SEER as a bad example. But yes.

MS. JOHNSON: Okay. Okay.

MS. BOSSLEY: Well, SEER was used for the original testing.

MS. JOHNSON: Right. And Christine?

MEMBER RITCHIE: Also, because the developers made it clear that the registry is how they gather the data, and that the registry was a focus. I think, when we looked at this, we thought there was claims versus registry, and that's why we evaluated it as such. But, essentially, what I think I understand you to say is that all of this data emanated out of registry-based data that then utilized claims data. Is that right? In other words, you didn't just look at claims data alone to come up with the numerator and denominator.

MS. BOSSLEY: Correct.

MEMBER RITCHIE: Which that was really where we were getting confused because we thought, if the data is only being driven by claims data, there are -- it's fraught with many more problems than with the registry. And we are familiar, you know, with how well ASCO has done with registry-based data in the past.

Arif, do you want to add to that? I

mean, clearly, you have some insight on this as well.

MEMBER KAMAL: Sorry. Can you -- I mean, Amy and I were side-baring, so --

MEMBER RITCHIE: No, we -- you know, when we had the conversation as a work group, we were basically worried that the claims data and the registry data were not of the same piece. And what our developers have told us is that they are of the same piece, and that provides some reassurance because we're more confident in the ability of the registry to gather the needed data elements than we are of claims data alone. Is that a fair representation of the difference between our thoughts at the work group meeting and today?

MEMBER KAMAL: So, for the registry, we mean SEER or do we mean QOPI or do we mean the Tumor Registry?

MEMBER RITCHIE: Why don't you tell us?

MS. BOSSLEY: So, yeah, we're using

registry, and it's awfully hard to use that to be specific. So the way this measure and, actually, all of the measures when we talk about claims are intended to be used -- and then let me talk about how the testing happened -- tended to first identify your denominator through a death registry of some sort, which is SEER or other things. And I believe we provided that information.

Then identified your patients, you move on, and that's where, for the purposes of how it was tested, they used claims data and identified, in this instance, ICU. And then, in the testing, they assumed death was correct based on SEER and looked to see, when they looked in the charts, did I indeed see a patient was admitted to the ICU versus the claims, and found a fairly high agreement rate.

CHAIR MORRISON: Yeah. And I think, Karen, to your question, I think, you know, the identification of the denominator through a death registry was critical to us, and not through claims, because we recognized claims was very poor for that. ICU through claims we recognized was very appropriate, and there are a number of studies, for example, Dartmouth Atlas, that have shown that to be both a reliable and valid measure of identifying ICU stay. Not death, ICU stay. Sorry. Stay. Stay. Stay.

So we were very comfortable with both the identification in the numerator and the identification in the denominator. Does that work for you?

MS. JOHNSON: It pretty much does. Probably what I'll do is write it up and get a few of you to just make sure that I've written it correctly.

CHAIR WALDROP: Great. Thank you. I think we can move on to feasibility. No?

MEMBER TATUM: That last discussion just hit at feasibility a fair amount. That data elements are pretty discoverable for what chronic data we were talking about, how to find the -- whether or not we can meet death, this meets a moderate level.

CHAIR WALDROP: Any questions or comments on feasibility of the measure?

(No response.)

CHAIR WALDROP: We're ready to vote on feasibility. Jean-Luc?

MR. TILLY: Yes. So, to vote for feasibility, just select 1 for high, 2 for moderate, 3 for low, or 4 for insufficient.

We're actually looking for just one more vote in the room.

The results are four voting high, 18 voting moderate, zero voting low, and zero voting insufficient. The measure passes feasibility.

CHAIR WALDROP: Thank you. We'll move on to usability and use.

MEMBER TATUM: Arif, feel free to help me out if I don't tackle this entirely correctly, but this is part of the medical oncology core measure set and use. It's going to be by virtue of that, CMS considers it for measure inclusion in Medicare quality programs. This is pretty useable.

Arif, anything to add?

(No response.)

CHAIR WALDROP: Sean or Christine, anything to add?

(No response.)

CHAIR WALDROP: Okay. Any questions or comments from the committee?

(No response.)

CHAIR WALDROP: Okay. Then I think we're ready to vote on usability and use.

MR. TILLY: To now vote for usability and use for 0213, select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient information.

The results are six voting high, 16 voting moderate, zero voting low, and zero voting insufficient information. The measure passes usability and use.

CHAIR WALDROP: Okay. And so, finally, we need to vote on the overall measure, whether we vote yes or no, we want to endorse this -- suggest that NQF endorse this measure.

MR. TILLY: Polling is now open. Vote 1 for yes and 2 for no.

The results are 22 voting yes, zero voting no. The measure is recommended for endorsement.

CHAIR WALDROP: Okay. Thank you for that important discussion.

So now we will move on to consider the third ASCO measure, which is 0215, proportion of patients who died from cancer not admitted to hospice. And I have the discussants as Gregg and Rob Sidlow. Gregg is not here. Or sorry. Rob is not here, so I'm looking to you, Gregg.

MEMBER VANDEKIEFT: Thank you. First ask the measure steward if you wish to say anything.

DR. EVANS: Just to add that this is the first of the three next ones that we have QOPI data for. So, hopefully, that will make things go more smoothly.

MEMBER VANDEKIEFT: Thank you. So

measure 0215, proportion of patients who died from cancer not admitted to hospice, measure steward ASCO.

So, looking at the data, about 30 percent of patients who die from cancer never do get referred to hospice, and only about seven percent actually have a documented conversation about hospice as a treatment option. Meanwhile, there is solid data demonstrating that earlier referral to hospice increases survival times, decreases resource utilization, and that the longer the enrollment time in hospice the better those benefits accrue.

And so another discrepancy that was noted in the data section or the evidence section was between Medicare and Medicaid hospice referral rates, namely, about 51 percent of Medicaid patients enrolled in hospice, Medicaid patients who died from cancer, compared to about 64 percent of Medicare patients.

And so, with that evidence together, it was felt that -- the staff that did the evaluation felt that there was a high level of evidence in support of this particular measure.

CHAIR WALDROP: Thank you. Any comments about this evidence, about this measure of evidence from the committee?

MEMBER VANDEKIEFT: And I should add -- I missed this -- that there was a limited amount of new evidence submitted. This was a maintenance measure originally endorsed in 2009, most recently endorsed in 2012. The interval evidence that was submitted is not qualitatively or substantively different. It mainly reinforces that. And that was through an expert panel through ASCO, which reviewed a number of RCTs as well as a Cochrane collaboration review. Both of those actually reinforced the evidence that was used during the previous endorsements.

CHAIR WALDROP: Thanks. Any discussion?

(No response.)

CHAIR WALDROP: Seeing none, we'll move to voting on the evidence for -- if we're okay with the evidence, we don't need to re-vote. Do we want to vote or just go through it? Okay. Sorry. I'm still stuck on the process of claims.

Okay. So --

MEMBER TATUM: Just a quick comment, if I may. In a world of being moderates at this table, isn't it exciting to celebrate that we have high evidence in palliative care and hospice?

MEMBER VANDEKIEFT: That's a sad statement.

CHAIR WALDROP: Thank you for that insight, Paul.

So we'll move on to considering opportunities for improvement and disparities.

MEMBER VANDEKIEFT: So gaps in the measure so, when you look at the data at the table that's before you, median hospice -- or median number of patients in different studies who died of cancer who were not referred to hospice, is in the ballpark of about 40 percent, which would indicate there is still a very substantial opportunity to improvement.

The question the staff raised was about racial or other level disparity. So, after the work group call, ASCO did submit some additional information. There are some differences between racial groups in terms of their rates of referral to hospice. It wasn't clear to me how statistically significant that was. Nonetheless, I think, across the board, there's pretty clear opportunity for improvement.

CHAIR WALDROP: Thanks. Any comments? Discussion?

(No response.)

CHAIR WALDROP: Okay. Seeing none, we do vote on opportunities for improvement. So, Jean-Luc, let us know when you're ready.

MR. TILLY: To vote on a performance gap for 0215, select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient.

The results are 20 voting high, two voting moderate, zero voting low, zero voting insufficient. The measure passes performance gap.

CHAIR WALDROP: Thank you. So we'll move on to looking at the scientific properties of this measure, and we'll start with reliability specifications in testing.

MEMBER VANDEKIEFT: The reliability concerns about this measure are very much similar to the previous two measures that were discussed, namely, the blend of claims-based data as well as registry-based data. After the work group call, ASCO did forward some information about different registries -- SEER, QOPI, et cetera, NDI, the National Death Index, I believe that is. And, across the board, it was felt that reliability, despite that, when you look at registry data, for instance, there's a kappa value of .679, so a substantial level of agreement there.

Claims data was really looked at more as a matter of face validity and so, combining all of that together in aggregate, the thought was that this would be a moderate level of reliability.

CHAIR WALDROP: Thank you. Any questions or comments on reliability of this measure?

(No response.)

CHAIR WALDROP: Given that there's no new evidence, we don't have to vote on this measure. I'm seeing head nods. Any objections to skipping a vote on this?

(No response.)

CHAIR WALDROP: Okay.

MS. JOHNSON: And just so I -- I don't want anybody to be confused about the process, and I know this feels a little different. But, just to remind you, with our new maintenance process, we're saying, if there aren't updates to testing and there aren't things that really require a lot of discussion, we may not need a re-vote.

So, unlike the other measures this morning where there was a lot of discussion about things like risk adjustment and testing, et cetera, you're not having that on this one. So we don't necessarily need to vote. So is that clear? I don't want people to be unhappy with our process.

CHAIR WALDROP: Thanks, Karen, for clarifying.

So we'll move on to validity testing and any threats to validity.

MEMBER VANDEKIEFT: So, in terms of validity testing, again, similar concerns to what were raised in the previous two discussions between claims and registry data. The claims data really, in many ways, the same population was used that Paul referenced in the previous discussion. 150 patients out of Dana Farber for the claims data, and then, for the face validity review -- make sure I'm on the right page here -- focus group with structured interviews of end-of-life cancer patients, bereaved care givers, et cetera.

At that point in time, the staff rated the validity as insufficient to do the poor sensitivity claims data. The numerator came up with about a .24 sensitivity compared to .96 specificity, but it was felt that with particularly the registry-based data that there was sufficient information there that that might bump that up to moderate.

CHAIR WALDROP: And is that what the work group aligned with?

MEMBER VANDEKIEFT: Yeah.

CHAIR WALDROP: Okay. Thank you for clarifying.

MEMBER VANDEKIEFT: That's what I remember, and Sean is nodding, so that tells me I'm probably right.

CHAIR MORRISON: See my brain this morning.

MEMBER VANDEKIEFT: Three hours earlier.

MS. JOHNSON: I have one question for the developer, just to make sure that I understand what you have. You talked about doing the QOPI nurse comparison. Did you consider the

QOPI nurse extraction the gold standard?

MS. BOSSLEY: I guess I would say yes. That was -- it was more than one extractor There were two, I believe, who were looking at that versus the chart. I don't know if I'm answering your question.

MS. JOHNSON: Or versus the registries? The registries -- you had a QOPI nurse extract and then compare that for the registry?

MS. BOSSLEY: Correct. Correct.

MS. JOHNSON: If that is the actual gold standard, then the question about what went on with face validity or what didn't go on becomes moot, because you have data element validity.

CHAIR WALDROP: If we have no concerns, we can skip a vote. Can I just ask if there are any objections to skipping a vote on the validity of this measure, or if there are any concerns, please raise them.

(No response.)

CHAIR WALDROP: Okay. Moving on, we will look at feasibility of this measure.

MEMBER VANDEKIEFT: So feasibility, again, this being a maintenance evaluation, no feasibility concerns were raised during the review in 2012.

Looking at this, however, there were concerns about the claims version and, there, the feasibility was felt to be fairly low for all of the reasons that we discussed in the previous measures, whereas, in the registry-based version, feasibility was felt to be high.

And I don't recall the work group coming to a particular consensus on this. My own recommendation would be that, if we're really focusing our emphasis on registries, that that would bump the aggregate feasibility into the moderate range.

CHAIR WALDROP: Any questions or comments on the feasibility of this measure?

(No response.)

CHAIR WALDROP: I'm sorry. I have to

clarify again. Do we vote to not?

MS. JOHNSON: Yes, we vote.

CHAIR WALDROP: We do need to vote on feasibility, okay.

MS. JOHNSON: Well, I mean, that actually is good point, if you feel like this is the same feasibility as the other two measures. So this is a little different than our new maintenance process. So, yeah, yeah, it's tricky.

You could carry over your votes from before, from the other two measures. Well, let me think about it.

Yeah, let's just vote.

CHAIR WALDROP: If there's any question, we should just vote.

Okay. So we're at a point to vote on the feasibility of 0215. Jean-Luc?

MS. TILLY: So, to vote for feasibility, please select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient.

The results are two voting high, 20

voting moderate, zero voting low, and zero voting insufficient. The measure passes feasibility.

CHAIR WALDROP: Thank you. So we'll move on to considering usability and use.

MEMBER VANDEKIEFT: Finally, usability and use. So, really, there are two main organizations that have been using this material. One would have been around in 2012, which is QOPI. And I don't believe the AHIP would have been doing that work in 2012, but American Health Insurance Plans medical oncology core measure set, and so that would be a new set of usability, which actually would increase the usability and use.

And so staff rated this as moderate, and I would endorse that.

CHAIR WALDROP: Thank you. Any comments? Questions? Discussion? Michelle.

MEMBER CAUGHEY: I noticed in the comments here that there might be a disincentive to refer patients to hospice for usability and use. I didn't understand why that would be the case.

MEMBER VANDEKIEFT: I'm not tracking you, Michelle. Where in the comments?

MEMBER CAUGHEY: Oh, I'm just -- where am I? Committee pre-evaluation comments. Yeah, there. I didn't understand that. Was that a sentiment that --

MEMBER VANDEKIEFT: That wasn't on my printed-out version, so let me read this. So that was a public comment, and I'm not really sure where that came from. And so I don't personally see that as enough of a detriment to usability and use to necessarily change my recommendation for moderate on this.

I don't know if anybody else here has a better understanding or --

MEMBER CAUGHEY: You don't -- nobody in the room sees this as a disincentive? Okay. So that's a weird comment.

MEMBER VANDEKIEFT: Yeah.

MS. CAUGHEY: Could that be referencing the three-day metric?

MEMBER VANDEKIEFT: That's a good comment, and I suspect that probably is more directed at the three-day metric than at the -- whether they were admitted to hospice at all or not. And it looks like that came out of the public comments section, so I would actually defer to staff here regarding that and what that might mean.

MS. JOHNSON: Yeah, I was just looking at these. I'm not seeing real quickly how --

CHAIR WALDROP: It's actually a committee ---

MS. JOHNSON: Right, but I think they were talking about it came from the public comment. So we were just trying to figure out what was said in the public comment that may have --

CHAIR WALDROP : So, Michelle, is this the section you're referring to, this -- so these would have been comments submitted through the pre-evaluation survey that committee members submitted. So maybe someone who is not here today submitted that comment, and so that's why we're not having more discussion around it.

MS. ROILAND: So I'd recommend we discount that comment; is that correct?

MEMBER VANDEKIEFT: I might modify that. Rather than discount it, just say, do we have a concern? And I've already heard you ask that question and nobody said no. I don't want to discount any comments if we don't need to.

CHAIR WALDROP: Okay. Thank you. So we'll go to voting for usability and use.

MR. TILLY: To vote for usability and use for 0215, please select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient information.

The results are two voting high, 20 voting moderate, zero voting low, and zero voting insufficient information. The measure passes usability and use.

CHAIR WALDROP: Okay. Thank you. And, finally, we'll move on to voting whether to recommend this measure as suitable for endorsement.

MEMBER VANDEKIEFT: Deborah?

CHAIR WALDROP: Yes?

MEMBER VANDEKIEFT: If I could just make two comments before we vote, kind of a point of personal privilege, if I may.

First off, thanks to Paul and Christine for running some heavy interference for me. But, secondly, there were some comments that I don't think are necessarily germane to this vote, but I think are germane to our stewards, which came from the Oncology Nursing Society regarding making sure that we have a clear distinction between hospice and upstream palliative care.

Some of the material that was submitted seemed to conflate the two, and I did not feel that that in any way undermined the validity of this particular measure or the evidence supporting it, but just that callout, keeping hospice and end-of-life palliative care somewhat distinct from early concurrent palliative care is something we need to be cognizant of.

CHAIR WALDROP: Thank you for clarifying that.

I think we're ready to vote on the overall suitability.

MR. TILLY: So, to answer the question, does the measure meet NQF criteria for endorsement, select 1 for yes, 2 for no.

The results are 22 voting yes, zero voting no. The measure is recommended for endorsement.

CHAIR WALDROP: Okay. Moving on, we will now consider measure 0216. And my notes indicate that both Amy has been recusing herself from these, but Christine also needs to recuse herself from this discussion.

The title of this measure is proportion of patients who died from cancer admitted to hospice for less than three days. And I'm going to ask our developer colleagues if there is anything else you would like to add about this measure before we start our deliberations.

DR. EVANS: No. I think it's very similar to the last one, just trying to give patience to the benefit of more hospice.

CHAIR WALDROP: Okay. So I note that Laura and Gregg are the discussants on this measure. And however you want to take this away.

MEMBER PORTER: We discussed this yesterday, so --

CHAIR WALDROP: Okay. So you have a plan? Thank you for that.

MEMBER PORTER: Yes, we have a plan.

CHAIR WALDROP: All right.

MEMBER PORTER: So this is the proportion of patients who died from cancer admitted to hospice for less than three days. It's an intermediate clinical outcome and a maintenance measure.

The developer did provide updated evidence for the measure, along with a diagram of the relationship, the process of care, and better patient outcomes. They also cited several sources, including three individual articles, 2013 Cochrane review, and a 2012 opinion from ASCO that supported this relationship.

Given the additional evidence, I recommend a high score and ask the committee to agree not to vote.

CHAIR WALDROP: Do I see any objections to Dr. Porter's suggestion not to vote? Are we good to go?

(No response.)

MEMBER PORTER: Okay. So the next -- sorry, trying to follow my notes here. So next is gap and improvement. Gap. It is unclear to me what is meant by the total patient population in the performance data. It is also unclear if the data represents all patients in the registry or just a sample. It is also difficult to ascertain if performance -- for me, I didn't understand the chart. If performance has gotten worse over time, patient level disparities data was not -- it was presented, but it needs to be provided at the practice level.

So I'd like some assistance on this as far as --

CHAIR WALDROP: Is it fair to ask if you have --

MS. BOSSLEY: We did run the analyses and provide to you the practice -- disparities data at the practice level. But I don't -- did NQF staff get a chance to send that to the committee? Because we have it here. We can read it off.

MEMBER PORTER: Okay.

MS. ROILAND: This is -- yes, we did send it, and we posted it to -- or we didn't send it. We posted it to the committee SharePoint page, and we sent an email out with a link to it. So I apologize if it was --

MEMBER PORTER: I am very sorry.

MS. ROILAND: That's okay.

MEMBER PORTER: No, I apologize for not seeing it. Okay.

CHAIR MORRISON: I looked at it.

There was a gap.

MEMBER PORTER: Thank you.

CHAIR WALDROP: Okay. Any questions or comments on opportunities for improvement?

(No response.)

CHAIR WALDROP: And I'm assuming we don't need to vote on this either, or we do? We do need to vote. Sorry, we do need to vote on -- okay. Offering an opportunity -- a rating of the opportunity for improvement.

So any questions or discussion before we vote?

(No response.)

CHAIR WALDROP: Okay, Jean-Luc?

MR. TILLY: On performance gap for 0216, select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient.

The results are 14 voting high, seven voting moderate, zero voting low, and zero voting insufficient. The measure passes.

CHAIR WALDROP: Great, thank you. So we'll move on to consider reliability and reliability testing.

MEMBER PORTER: Yes. A calculation algorithm is provided. The abstract tool used in the QOPI was not provided. It is unclear how the denominator will be generated in the claims data. I think this is what we've talked about before.

A reference is made to a death registry, but it is not explained how it will be used. It is unclear how patients in the denominator who used hospice outside of Medicare are identified.

CHAIR WALDROP: Okay. Questions and comments on -- is that something that -- I'm wondering if the developer would want to address the question about outside of hospice.

MS. BOSSLEY: You mean the question Medicare versus -- so part of this, we're limited with the data set that was available at the time this was tested, which was Medicare data, which is why you see it specific to this. Our hope is, now that it's on the core measure set list, we can start having conversations with commercial health plans, Medicare Advantage plans, others, to answer this and begin to look more broadly. But, unfortunately, we're limited, at least with the claims, to that piece.

QOPI, though, is all patients within that practice, so that at least reflects a broader look by pair.

CHAIR WALDROP: Thank you.

MEMBER PORTER: Thank you.

CHAIR WALDROP: Any other thoughts or comments about reliability?

(No response.)

CHAIR WALDROP: Okay. I think we're ready to vote on the reliability of this measure.

MR. TILLY: Again, this one is a little bit different since we don't have the data elements. So to vote for liability for 0216, select 1 for moderate, 2 for low, 3 for insufficient.

The results are 18 voting moderate, three voting low, zero voting insufficient. The measure passes reliability.

CHAIR WALDROP: Thank you. Moving on, we'll consider validity testing and any threats to validity that were identified.

MEMBER PORTER: I think we did discuss the question about using the three-day as opposed to seven-day as a measure for -- as a threshold for the appropriate enrollment in hospice. The developer stated that a three-day threshold is the minimum lowest bar and easier to obtain. They also noted that it was a better indicator of quality of care.

And then -- okay. Also, there was no updated testing information presented, and does the committee think we need to vote on reliability if no new information is presented? The previous score was moderate.

CHAIR WALDROP: We just voted on reliability. We're in validity.

MEMBER PORTER: Oh, shoot. I'm sorry. I'm following this horrible thing I printed out, and it's not very good.

CHAIR WALDROP: Okay.

MEMBER PORTER: So where are we, validity?

CHAIR WALDROP: Validity, yeah.

MEMBER PORTER: Oh, my goodness. Okay. For validity -- and I don't think this came up in the previous ones, but for the registry data, a QOPI nurse abstractor was used. The question is whether the abstractor is considered an expert, and what is used as the basis for claiming them as an expert, and also, you know, to guarantee that it's a standard.

The sensitivity was .97, and specificity was 1 for administrative claims data. A face validity assessment was done utilizing a focus group, but the results of the focus group were not provided. It is difficult to ascertain if the measure is an indicator of quality.

CHAIR WALDROP: Okay.

MEMBER PORTER: And then do I do threats to validity also?

CHAIR WALDROP: Yes, if you have --

MEMBER PORTER: Okay. I'm going by

the questions I answered in the -- yeah. Okay.

It is not clear if there is a need for risk adjustment. It is also not clear if the claims data and registry data are comparable. It needs to be determined if the nurse extractor is the gold standard. And it did receive a low rating from the staff, insufficient rating from the staff on validity.

CHAIR WALDROP: Gregg, did you want to add to that or --

MEMBER VANDEKIEFT: Yeah. And I would simply add, very much as we talked about the use of the nurse abstractor as the gold standard with the previous measure, the fact that this is done in a comparable manner, I would advocate, bumps this up to a moderate level of validity.

CHAIR WALDROP: Thank you. And I just want to offer our developer colleagues -- if there's anything more you want to say about the gold standard or if you think it's covered with previous discussion.

MS. BOSSLEY: The testing was all done

at once, all of these measures. So the same abstractors were abstracting across the three measures.

CHAIR WALDROP: Okay. Other -- Tracy?

MEMBER SCHROEPFER: I just have one question. I'm sorry. Can you -- to the developers, why three days is easier to collect than seven. I'm just curious.

DR. EVANS: I don't know that it's easier. We actually collect both in QOPI.

MEMBER SCHROEPFER: Okay. Well, it was just noted in the thing that it was, so I just wanted to know. Thank you.

DR. EVANS: I wouldn't say that it's easier to collect. I don't think it is easier. We actually collect both in QOPI. We get both three-day data and seven-day data.

MEMBER VANDEKIEFT: Yeah. And I was just going to follow up that the developer did, after our work group, call and submit a comment that is available on the SharePoint site addressing that and noting that, in the future, they do have the hope to do the seven-day data. It's just that, right now, there's such a variation in practice across different settings, and three days has been the ones that has been used. And so that is still the standard. But everybody recognizes that longer is better in this setting.

CHAIR WALDROP: Thank you for that. Other comments or other points for discussion?

(No response.)

CHAIR WALDROP: Seeing none, I think we are ready to vote on the validity of measure 0216.

MR. TILLY: Again, this one is a little bit different, since we looked at face validity only. Select 1 for moderate, 2 for low, 3 for insufficient.

The results are 19 voting moderate, two voting low, zero voting insufficient. The measure passes validity.

CHAIR WALDROP: Thank you. We'll move on and consider the feasibility of 0216.

MEMBER PORTER: The feasibility is similar to what was stated in the others with the measurement. The data elements are routinely generated during care of delivery, delivery care, the issue of claims version, and the possible need for a death registry data. And then, again, with the non-Medicare hospice patients, which they've explained.

CHAIR WALDROP: Thank you. Any comments or concerns? Questions? Margie?

MEMBER ATKINSON: Okay. Can we get a comment on the low rating from NQF? Am I seeing that, under feasibility?

MS. JOHNSON: Yeah. It was really the question about -- really the two questions that I think have been answered. One is how do you get the death data if you're using claims data. So it was from a death registry.

The second was the question about Medicare hospice benefits. So, if you're looking at claims but you don't -- if somebody is not on Medicare, then you can't see if they were in hospice. So I think he answered that.

CHAIR WALDROP: Any other questions or comments?

(No response.)

CHAIR WALDROP: Seeing none, I think we are ready to vote on the feasibility of measure 0216.

MR. TILLY: To vote on feasibility, select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient.

The results are three voting high, 16 voting moderate, two voting low, and zero voting insufficient. The measure passes feasibility.

CHAIR WALDROP: Great, thank you. So, moving on, we'll consider the usability and use of measure 0216.

MEMBER PORTER: Okay. This measure is not being publicly reported, but it is part of AHIP just like the previous one, and it will be included in the Medicare quality programs. The number of practices has increased, but the average performance has not.

The developers did not list any potential harms, but a public comment cautioned that providers may be disincentivized to refer patients to hospice if they are actively dying.

The benefits of the measure outweigh any potential unintended consequences. I believe the measure has the potential to indicate a need for more hospice facilities and an education of both providers and patients.

CHAIR WALDROP: Thank you. Do we want to consider the disincentivization again? Is that a word? The possibility of it being disincentivized. Sean?

CHAIR MORRISON: I think the benefits of this so far outweigh the disincentive that I think it's, hypothetically, theoretically possible. But the benefits far outweigh the risk.

CHAIR WALDROP: Tracy, do you have -- oh, sorry.

(Simultaneous speaking.)

CHAIR WALDROP: Gregg?

MEMBER VANDEKIEFT: Maybe just a corollary comment on that. As Paul was pointing out to me, we suspect that the disincentive concern is really largely targeting inpatients who are being referred to GIP hospice to try and improve inpatient mortality data, and some of the misuses of hospice situations there. But Sean said it exactly right. I really believe that the benefits so clearly outweigh that that we don't need to give that a lot of weight.

CHAIR WALDROP: Great. Arif?

MEMBER KAMAL: And, Deborah, I'm just reminding myself, so that the Oncology Care Model measures were just released a couple of weeks ago, and they've included this as an outcome measure, along with risk-adjusted all-cause hospitalization in the last six months and risk-adjusted all-cause ED visits in the last six months, hence, to our developers regarding potentially using that.

But the point being I think they're using that as a balance measure that says, you know, not in our ED, not in our hospital. Get them to hospice. So I think that's how they're balancing it.

CHAIR WALDROP: Great. Thank you for that. And woohoo on that data. That's awesome.

Any other comments? Any other discussion?

MEMBER PORTER: I gave it a high rating.

CHAIR WALDROP: Okay. Thank you for that.

So that brings us to voting on the use and usability of measure 0216.

MR. TILLY: That's right. Select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient information.

The results are 13 voting high, eight moderate, zero low, and zero insufficient information. The measure passes usability and use.

CHAIR WALDROP: So that brings us to the final vote, which is whether or not we recommend this measure as suitable for endorsement by NQF.

MR. TILLY: To answer the question, do this measure meet NQF criteria for endorsement, select 1 for yes and 2 for no.

The results are 21 voting yes and zero voting no. The measure is recommended for endorsement.

CHAIR WALDROP: Okay. Thank you. We have one more measure before we take a break. We're going to consider 0210. And the title of that measure is the proportion of patients who died from cancer receiving chemotherapy in the last 14 days of life.

And let me start by asking our developer colleagues if you have anything you want to add about this measure.

DR. EVANS: Just that this is 14 days, whereas were 30 and three. And chemotherapy is defined as any antineoplastic therapy, be it IV or oral.

CHAIR WALDROP: Okay. Thank you. So

I have Amy also recusing herself on this measure, and I have our discussants as Rob and Laura. So are you willing to take that away, Laura?

MEMBER PORTER: Where's Rob?

CHAIR WALDROP: He had a family emergency and --

MEMBER VANDEKIEFT: Rob had prepared to present this one and was planning to be the lead discussant on it.

CHAIR WALDROP: Okay. Okay.

MEMBER PORTER: I'm going to need a minute.

CHAIR WALDROP: So sure.

MS. JOHNSON: If you guys can hold off, I think we could do it. Staff could help you work through this one. It would just kind of be nice to finish this up and let ASCO -- oh, okay. Okay. I'm sorry.

CHAIR MORRISON: Yeah. If we can move through this with staff, I think -- you know, this is very similar to all of the others that we have done, but I think some of the same issues are going to come up or not come up. So I think, if we can push through, let's.

CHAIR WALDROP: Perhaps it would be helpful if we could ask the measure developers just to give us a little overview. I am stalling for time, yes. Trying to give Laura a minute here.

DR. EVANS: This was developed the same time as the others and as part of our QOPI program, so something that oncologists are measuring their own performance on. Let's see. Do you have pulled up any concerns that came up on the --

CHAIR MORRISON: So, I mean, I can -- let me take a crack at this while you're doing that since I actually had looked at all of these.

So I think the evidence from this was considered to be relatively strong. There were some very good studies that found that intense chemotherapy was related to outcomes that we consider both unwanted and potentially harmful to patients.

I think the only question in terms of the evidence that needed to be really directly addressed -- and I think this came up in the work group discussion -- was the definition of chemotherapy, guys, and whether -- I know that that encompassed, but how this, in terms of the evidence with some of the new oral, nontoxic agents, whether (a) those were included, and (b) how those were dealt with, because there wasn't -- the evidence that was presented was typically along what we traditionally think of as chemotherapy.

Does that make sense? I know I'm sort of being a little inarticulate.

DR. EVANS: It does. I mean, I wouldn't say any therapy is nontoxic, and they are included -- they have been included in the definitions, although, right, they don't have the same data as the traditional set of toxic chemotherapy. They're sort of too new, when we're talking about the targeted agents, or even more complicated immunotherapy.

MEMBER PORTER: I'm sorry. I missed that part. So are you including them or just it just the cytotoxic?

DR. EVANS: All antineoplastics. The only thing excluded specifically is hormonal therapy.

MEMBER PORTER: Okay.

DR. EVANS: And, just to point out, too, there's not just toxicity to -- traditional toxicity. There's also financial toxicity that needs to be considered.

CHAIR MORRISON: That's not what my oncologists say.

MEMBER PORTER: Okay, I've got mine up now.

CHAIR WALDROP: Okay.

MEMBER PORTER: Thank you.

CHAIR WALDROP: Other comments on the evidence, Laura?

MEMBER PORTER: Yes. The evidence has been presented in mostly recent literature. The literature is tangential in that none of the articles show the relationship between discontinuation of chemotherapy and desired outcomes, that of negatively impacting the patients' and care givers' experience. So it doesn't directly show that.

Although the recommendation that you shouldn't have palliative care early in the process of treating metastatic patients makes sense, they would still be able to receive all treatments, including chemotherapy, radiation, and/or biologics.

So the transition to hospice before the last two weeks of life would be critical -- and this is not addressed. What did I just say?

CHAIR WALDROP: Any comments from the staff in terms of helping us get through this?

MS. JOHNSON: We actually tried to note, you know, kind of what we thought the evidence that was presented did, and it did seem a little tangential. It's one of these places where there's not systematic reviews with grading, so you're relying on these articles.

So the question for you as you consider the articles that were provided, is are they really relevant to the focus in the measure and do you feel like that you're getting the body of the evidence, you know, that what's there is actually presented to you.

I don't think I've said this, and this is true of not just this measure or ASCO measures, but just in general. While we accept clinical opinion and it's important, we don't really count that as evidence per se. We are looking for empirical evidence. So that's why, even though we know the clinical opinion from ASCO is listed, you know, that doesn't count as NQF-level evidence.

And, again, that's not specific to this particular measure; it's true across the board. So I think, again, the question for you is how closely this hits the measure focus, and is this pretty much what we have to work with.

CHAIR WALDROP: Thank you. So I have

comments from Sean and Karl and Arif.

CHAIR MORRISON: So I'm going to take my chair's hat off and put my member's hat on.

Two issues that I think need to be addressed. I think this is the opportunity to really begin to look at -- and to weigh in on unnecessary and unneeded and potentially toxic treatments for somebody who will not benefit.

And, yes, I understand that the baseline on this should not be zero -- shouldn't be zero, but there should be a relative baseline on this. I think the evidence that's supported, I agree, is probably low. On the other hand, I would suggest that this is one of those where you don't need a trial to demonstrate that a brick falls when you throw it.

And I think there's an opportunity, Karen, to even move this with insufficient evidence, with exception if that's the case. But I really believe that this is one where the evidence and the face validity pushes us forward.

CHAIR WALDROP: Thank you. Karl and

then Arif, and then Paul.

MEMBER STEINBERG: And I guess I have two concerns. One has already been mentioned, that some of these chemo regimens now, the oral regimens, you know, that people are tolerating them well and so on. I'm not sure that that's -- just that, empirically, that that's something that somebody should get dinged for. And I'm the first person to, you know, point the finger at oncologists for doing too much and so on.

And the other point is, obviously, sometimes people die from -- you know, they may be getting their first round of chemo, and they have some complication that's either unrelated to chemo or is related to chemo where, again, you know, I don't know that the oncologist should get slammed for that.

CHAIR WALDROP: Thank you. Arif?

MEMBER KAMAL: So I actually think the greatest evidence around us linking quality of life and quality of death to use of chemotherapy near the end of life comes from Holly Gregerson's

Lancet -- JAMA Oncology article from last September, which took six sites and asked bereaved family members regarding their impressions of quality of life in the last week of life, not the last two weeks of life. But in the last week of life, and correlated, you know, receipt of chemotherapy to truly lower quality of life. So there was that direct correlation with a large sample size of patients.

I think, to the issue of what the actual medication is, you know, even though immunologics and biologics and vaccine therapies and so on are new and, frankly, novel, we have yet to see, you know, the type of data that shows dramatic changes in that last -- in the first two weeks, let's say, if the start was day minus 15, that would really justify us doing that.

So they're exciting. They're new. They're novel. But they're really novel based on their mechanism of action and, to a certain extent, efficacy in places that didn't have efficacy before.

But what we are seeing with things like new biologics and other things are, you know, survival differences are measured in months now, right, where some of the pressure for survival we're seeing is not within that 14-day window. So I don't think there is something to be lost by saying we throw this miracle at somebody on day minus 15 and then 10 percent of them, something good is going to happen so it justifies us doing that.

CHAIR WALDROP: Thank you. I'm going to jump the line here and ask Bob to share his comment. We understand there's a comment from Bob on the line. Bob, are you there?

MEMBER ARCHULETA: Yes. This is Bob. Just from an anecdotal perspective and a pediatric perspective, what I'm seeing in the pediatric world is cloaking chemotherapy, is tired of chemotherapy and, therefore, continuing that until the last days of life and happening more and more frequently, certainly in the patient population that I take care of. And I think that that's something that we need to be aware of.

CHAIR WALDROP: Thank you. Paul and then Linda?

MEMBER TATUM: Brief question. I'm perfectly accepting that we could talk about insufficient with exception given the new gaps on the oral agents and the possibilities they concur together. But I was just going to ask, the prior score on this level was?

CHAIR MORRISON: It was low initially from staff, Paul.

MEMBER TATUM: From this one. But the earlier submission?

CHAIR MORRISON: Presumably, moderate.

MS. JOHNSON: I don't have that in front of me and, at the time, we had different -- we didn't have the evidence algorithm. So, yeah, it was a little different, so it's probably not -- it did pass. It did pass.

So, just to make sure that we're all on the same page here, there are a couple of articles that were cited, particularly Greer and Landrum, as well as the one that -- did you share that with the committee, Arif? I don't remember if that was one of the ones, but it seemed familiar when you mentioned it, so I think you probably talked about that on the work group call.

So, really, the question there is, if that's pretty much what's done -- because there's not going to be clinical trials on everything, right? And that's fine. We don't insist on having our CT, so that sort of thing. So, if that's what's available and that's what's in front of you, then you can go that direction.

That's just the question. And you guys will know better than staff will as to whether that is everything.

CHAIR WALDROP: Thanks for clarifying. Linda and then Christine?

MEMBER SCHWIMMER: I just had a clarifying question for the developers and then the committee about the articles. So death from cancer, that's the terminology that's used in the numerator and the denominator. Does that include something like a fall or an infection? I mean, I'm just trying to get a sense of what's included which, I guess, is similar to the earlier comment.

DR. EVANS: It's left to the discretion -- the way it's used in QOPI, it's left to the discretion of the oncologist. It does specify cancer or the treatment of that cancer. I think infection would certainly, for most oncologists, fall in that category. Getting hit by a truck probably wouldn't.

CHAIR WALDROP: Thank you.

MEMBER SCHWIMMER: So in the articles describing it, it was fairly broad once there was the diagnosis, if it was at all related, like not the truck incident, but pretty much anything else?

DR. EVANS: Correct.

MEMBER SCHWIMMER: Okay.

CHAIR WALDROP: Thank you. Christine?

MEMBER RITCHIE: Just following up on the Prigerson article. So one of the nice things about that article is actually it is any chemotherapy.

CHAIR WALDROP: Okay. So all-inclusive.

MEMBER RITCHIE: Was not associated with increased survival in the last week of life.

CHAIR WALDROP: Okay. Karl --

MEMBER RITCHIE: Any chemotherapies. We were talking about the heterogeneity of chemotherapy and, in that Prigerson article, they didn't differentiate.

CHAIR WALDROP: Okay. Thank you. Any other comments or discussion on this measure before we vote on the evidence?

DR. EVANS: Can I add one more thing just as an oncologist?

CHAIR WALDROP: Sure.

DR. EVANS: Just to say that you can get dinged for a first course of chemotherapy if a patient dies. I think that's what's makes this actually a good metric, because you don't want that to happen either. And this isn't just a palliative metric where oncologists, you know, want to make sure they're not giving chemotherapy too late in the game. They also don't want to give chemotherapy that's too toxic and make sure that they're doing appropriate supportive care.

So I don't see that as a ding to the metric. I see that as a benefit.

CHAIR WALDROP: Thank you.

MEMBER PORTER: So is the recommendation then to vote insufficient and then pass it with the evidence -- pass it with the exception? I think that's what you were saying, Sean.

CHAIR WALDROP: Do you want to take that?

CHAIR MORRISON: So I think -- I mean, actually, this is an important point, and let me try and summarize the group discussion so that the vote doesn't go where people don't think it will go.

So we've heard that there are initially data that primarily will examine the effect of what we typically consider to be intravenous toxic chemotherapy, cytotoxic therapy, within 14 days of death, and that was associated with poor outcomes. What Arif and Christine have raised is a relatively recent study that looked at the effect of all chemotherapy, including, quote, unquote, the -- as my oncology group says, nontoxic oral therapies. Apologies to the measure developers.

And I really like, quite honestly, Tracey, your comment about financial toxicity as well. And demonstrated that -- and correct me, guys, if I'm wrong -- demonstrated no improvement in outcomes.

And other -- I'm sorry, Arif. I can't remember this, and I read it -- hospice -- other outcomes that were -- it was simply no improvement. Quality of -- right, right, right.

So that, if people believe -- and this is, you know, sort of the difficult part. If you believe that that, as a group, forms enough evidence to move this measure forward, then, you know, that puts it into the moderate or you're very optimistic, the high category. If you believe that -- actually, that the evidence does not exist at all or -- then you need to go into the insufficient. And, if there are enough people who believe that, then we will move to voting for exception or not.

Does that help people?

CHAIR WALDROP: Thank you for clarifying. Comments? Paul?

MEMBER TATUM: I don't know that there's a big -- it's reassuring that there's the opportunity to revisit this should we split 50/50, similar to previous parliamentary maneuvers, in case my prior comments sway anybody inappropriately on that first vote.

CHAIR WALDROP: So let me just make certain that that is the case. If it's split, we would have the change to re-vote or no? We really shouldn't do that?

CHAIR MORRISON: We really shouldn't. I think -- let me try this again. Let me -- since, I think -- let me -- what I'm hearing from the group is there is relative comfort level with the prior data that focuses on the toxic effects of quote, unquote, what we grew up with as chemotherapy, okay, and that, if we didn't have the newer biologic and the vaccines, that there would be sort of agreement around the group.

I think what I'm hearing is that people -- the committee, the work group -- were concerned about whether putting in the newer agents changed the evidence level. And what I'm going to do is I'm going to ask Dr. Kamal again, because there is a new paper that is a multi-site trial, if he could again summarize the data from that and see if that pushes people into whether they feel the evidence is low, moderate, high, or still insufficient.

Does that make sense? Arif?

MEMBER KAMAL: Yeah. And I'm not going to try to confuse the picture. It's helpful that ASCO has provided sort of a standardized definition of what's antineoplastic therapy. Note that that's the term they use, which I think is the term we used in palliative care to a cancer-directed treatment, which is truly all-encompassing minus hormonal therapy, which is just a good caveat to add.

The Prigerson article was looking longitudinally at patients across multi institutions who, between 2002 and 2008, so it is an older study that would not technically include the agents that we have today. So I'm going to say that. That is a limitation of the study.

But what they found is that, at the time, you know, general cytotoxic therapy was not helping with quality of life, quality of death as a composite measure, which includes the reflections on the brief care givers regarding whether it was a good death experience by being on active chemotherapy at the time.

I think ASCO, in a standardized way, and I think in the oncology profession in a standardized way, we are looking at novel agents not any differently in terms of their efficacy in the last two weeks of life.

There are multiple clinical trials, for example, that have shown that there are some quality of life benefits for single-agent chemotherapy in very specific populations like single-agent dose attacks on lung cancer patients, but they have to have a performance status that would not otherwise tell us that they are going to die in two weeks, right?

So this is a performance status issue. If a performance status two patient get dose-reduced, dose-taxed for second or third line therapy and then dies within two weeks, one would question either the prognostic ability of the oncologist or some -- you know, unobserved factors that should have played into that which is to Tracey's comment, which is that we don't -- we want to be able to predict that up-front.

CHAIR MORRISON: And I think the other comment I would make that might be helpful before we vote is that, if this committee was the endocrine committee or the orthopedic committee or, indeed, the oncology committee, and we were looking at a quality measure that looked at a new therapy or drug, we would be saying, does this have benefit rather than does this have side effects.

And I think we, because of where we come from, tend to look at this as does this have harm rather than it does have burden. And I think what Arif has been pointing out is that we need to think about both is there evidence that demonstrates this has harm, but also is there evidence that shows that this has benefit, and is that presented because, obviously, we don't want to be administering a therapy, a medication, or a treatment to somebody that has absolutely no benefit moving forward.

Does that make sense to people? Does that help in terms of where people might come down on?

CHAIR WALDROP: Yes. Thank you very

much for the energy to clarify that. Do you have something more?

CHAIR KAMAL: And note that, in the body of what's presented here is this idea that it doesn't have to be zero, right, that this is used to compare performance. There are certain clinical scenarios where we do continue certain things up until death because we worry about tumor flare if we suddenly stop it. But the idea is that, you know, that should even out across a large population.

CHAIR WALDROP: Thank you. Anything further before we vote on the evidence?

(No response.)

CHAIR WALDROP: Seeing none, we're ready to vote on the evidence for 0216.

MR. TILLY: Yeah, that's right. To vote on the evidence for 0210, select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient.

Okay. The votes are one voting high, 19 moderate, one low, one insufficient. The measure passes evidence.

CHAIR WALDROP: Thank you. Moving on, we'll look at gaps in care and opportunities for improvement as well as disparities.

MEMBER PORTER: So the performance data was provided, but the disparities information was not. Although the number of patients was presented, yeah, the racial breakdown wasn't clear. It is not clear if the performance got better because the numbers indicate that more patients are being reported on, but not what the results are. So I wasn't clear about whether or not there was improvement.

CHAIR WALDROP: Other comments on opportunities for improvement, gaps?

DR. EVANS: The disparities data, I think, was provided. I think it's the same thing. This must have been that same link, correct?

CHAIR WALDROP: Thank you. Any other comments on opportunities for improvement or gaps?

(No response.)

CHAIR WALDROP: Seeing none, we'll move to voting.

MR. TILLY: To vote on performance gap for 0210, select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient.

The results are one voting high, 21 voting moderate, zero voting low, and zero voting insufficient. The measure passes performance gap.

CHAIR WALDROP: Thank you very much. So we'll move on to look at reliability testing and just reliability in general. Laura?

MEMBER PORTER: The only issues I had about reliability have already been addressed in the previous discussions, so it's -- I don't have anything to add.

CHAIR WALDROP: Okay. Thank you. Any other comments or discussion about the reliability of this measure?

(No response.)

CHAIR WALDROP: We could suspend a

vote if there are no issues. Any objections to suspending a vote on this measure, on the reliability of this measure?

(No response.)

CHAIR WALDROP: Okay. Then we'll move on validity, to considering the validity of 0210.

MEMBER PORTER: Okay. I'm not sure if it is clear from the data whether this measure is an indicator of quality of care and what the definition of quality of care is. It is not clear -- oh, that the patients who died -- you just -- I'm sorry. You cleared that up for me. It's treatment-related and also death from cancer, so that's not the issue there.

Also, better end of life, I think that's kind of subjective, but are there measures to qualify that?

CHAIR WALDROP: Are you asking the developers to address that?

MEMBER PORTER: Yes.

CHAIR WALDROP: Okay.

DR. EVANS: Well, I'm getting

philosophical. I mean, I think utility of therapies or participating in therapies that provide no benefit is a negative factor in and of itself. So does that answer your question?

MEMBER PORTER: Yes. Yes.

CHAIR WALDROP: I would just like to ask the staff to comment on the preliminary determination of insufficient validity on this measure.

MS. JOHNSON: It was the same thing that we now know the answer about in terms of claims and use of death registry data. And then, for the actual registry testing, you can use the results that they presented up in the reliability section as validity as long as they agree that the QOPI nurse was the gold standard. And they said that they have.

So what you have then is testing for both levels of analysis at the data element level, and it kind of makes the question about the face validity moot.

CHAIR WALDROP: Thank you so much for

clarifying. I appreciate that.

Any other questions about validity, with respect to validity, before we vote? Arif?

MEMBER KAMAL: So I'm going to channel my inner Tom LeBlanc in saying this. It's a good measure, and I think it's valid. We should just make a note, though, that for heat malignancies, sometimes those patient populations are different. A bone marrow transplant and other things work. For example, you know, patients with leukemia will stop chemotherapy and die three or four days later. Those are sort of acute processes where we stop. Death is imminent, and we stop because we recognize that death is imminent. But it falls within that 14-day window.

I don't think that's an argument for risk adjustment right now. I think it's just something to note, that there are other sort of -- all cancers are not all cancers, right, that there are populations that -- in the future, I think we would hope that there may be a potential new measure that addresses heat malignancies or bone marrow transplant or something else.

CHAIR WALDROP: Thank you for that perspective. We appreciate it.

Anything else? Christine?

MEMBER RITCHIE: So, Arif, that's an incredibly important point, and I wonder if there should -- is there a way that we could just, you know, encourage ASCO even now to look at the hem-onc or at least the bone marrow transplant differential? Because that seems to be a fairly important issue.

CHAIR WALDROP: Do you want to comment?

DR. EVANS: I mean, it's certainly something we could look at. And I guess I have a question for Heidi. If we do -- if we're going the risk adjustment anyway for the ED visit one, can we apply that to all of these measures?

MS. BOSSLEY: I think, if we're going to do it, we should do it for all and see what we find, yeah.

CHAIR WALDROP: Thank you for that good discussion. Anything else before we move to vote?

(No response.)

CHAIR WALDROP: Okay. Seeing none, I think we are ready to vote on the validity of 0210.

MR. TILLY: That's right. And, again, this one is a little bit different. So, to vote for validity for 0210, since we had face validity only, select 1 for moderate, 2 for low, 3 for insufficient.

The results are 22 voting moderate, zero voting low, zero voting insufficient. The measure passes validity.

CHAIR WALDROP: Thank you. Moving on to consider usability and use of this measure. Sorry. Sorry. Feasibility. Can't do that. We have to go back to feasibility.

MEMBER PORTER: Usually, I'm the one doing that.

So feasibility is the same as the previous measures, the QOPI registry and the administrative claims.

CHAIR WALDROP: Okay. So an economy of scale here. We've already considered this issue. Any other comments or discussion about feasibility of this issue, of this measure?

(No response.)

CHAIR WALDROP: Do we want to carry over the vote from before? Any objections to carrying the vote from previous measures?

(No response.)

CHAIR WALDROP: Okay. Moving on, now we will consider usability and use. Any additional issues on this measure, Laura?

MEMBER PORTER: No. No. I think it's a good measure and, you know, just what I've brought up before, that it's been addressed.

CHAIR WALDROP: Okay. And can we forego a vote on this, too?

MS. JOHNSON: I think I'm going to ask you to actually do the vote on this one because the last time you actually did vote because there were questions about usability and use in the programs, et cetera. And I'm not quite sure which vote we'd be carrying over at that point, so --

CHAIR WALDROP: Fair enough. Absolutely. Okay. So any discussion before we vote on the usability and use of 0210?

(No response.)

CHAIR WALDROP: Okay. We'll move to voting.

MR. TILLY: To vote for usability and use for 0210, select 1 for high, 2 for moderate, 3 for low, and 4 for insufficient information.

The results are three voting high, 19 voting moderate, zero voting low, and zero voting insufficient information. The measure passes usability and use.

CHAIR WALDROP: Thank you. And, finally, we will vote on whether or not to recommend this measure as suitable for endorsement.

MR. TILLY: To answer the question, does the measure meet NQF criteria for endorsement, select 1 for yes and 2 for no.

We're actually looking for just one more vote in the room.

CHAIR WALDROP: There it goes. Yeah, we're at 22. We're good. We're good.

MR. TILLY: Thank you for voting. The results are 22 yes, zero no. The measure is recommended for endorsement.

CHAIR WALDROP: Okay. So this brings us to the close of our session on the transitional measures. I want to thank our colleagues from ASCO for being here to walk us through, and to each of you for the good conversation and discussion about these measures.

And Karl has a comment before we close.

MEMBER STEINBERG: I was just hoping that maybe right before we reconvene to continue working, maybe we could get a picture that I could post on Twitter of those who don't mind being in like a group picture.

CHAIR WALDROP: Thank you. We'll take a break and we'll resume at five minutes of 11:00? We'll resume at five minutes of 11:00. Thank you.

(Whereupon, the above-entitled matter went off the record at 10:41 a.m. and resumed at 11:00 a.m.)

CHAIR MORRISON: All right. Are we ready? Is everybody -- everybody's back. Perfect.

Okay. So we are going to go to our final measure or series of measures which is the CAHPS Hospice Survey. I am going to ask our developers to introduce this measure, which is really in many respect is a composite measure. And once they introduce the measure I am going to walk us through how we are going to address this one because it's a little bit different from some of the others we've, we've done over the past two days.

So, we have CMS here, I gather.

MS. DEAN-WHITTAKER: Sorry. My name is Debra Dean-Whittaker. I work for CMS. And I am the contracting officer's representative for the CAHPS Hospice Survey. That means I'm the project officer.

With me I am very lucky to have Dr. Rebecca Anhang Price from the RAND Corporation. She is our project director for RAND. We worked very closely with RAND in both the development of this survey and also its implementation.

Also, on the phone is Dr. Layla Parast who is in California and got up early to be able to be with us. She is the statistician and is available to answer your questions as well.

The CAHPS Hospice Survey is an experience of care survey. The respondents are the primary care givers of patients who died while under hospice care. The primary care giver is provided to us by the hospices from their records.

All hospice settings are included in the Hospice CAHPS Survey. All payers are included.

Data collection begins after a lag of two months after the death of the patient. So a patient dies in January, their primary care giver will not be contacted until April.

The modes of survey administration are mail only, telephone only, and mail with telephone follow-up.

Survey administration began nationally in January of 2015 with a dry run during the first quarter, which was intended to give hospices and their vendors an opportunity to work together, and also to learn how to submit data to our data warehouse. That data is not going to be publicly reported.

After our first quarter we have ongoing monthly implementation of the survey. Coincidentally, today is the deadline for survey vendors to submit fourth quarter 2015 data to the Hospice CAHPS warehouse.

The Hospice CAHPS questionnaire has a total of 47 questions. All respondents do not always answer all questions, but they generally do answer most of them and -- or we ask them to. The measures we have submitted to you today are all based on survey items.

CMS has plans for this data. We do hope to publicly report CAHPS Hospice Survey data on the medicare.gov website. You may be familiar with similar reporting for home health or for hospital currently on the Medicare website.

We expect and anticipate public reporting will start in the summer of 2017. And we plan to report a rolling four quarter average. Hospice CAHPS is also an element of the CMS Hospice Quality Reporting Program.

And for a short bit of background:

The survey was developed by the Centers for Medicare and Medicaid Services, working closely, as I said, with our contractor. It was allowed to receive the CAHPS trademark by the Agency for Healthcare Research and Quality, who are the owners or holders of that trademark. And, therefore, it is part of the AHPS -- the

AHPS? -- the CAHPS survey family.

Thank you.

CHAIR MORRISON: Questions for the developer before we move forward?

(No response.)

CHAIR MORRISON: So, as was noted, this is a 47-item survey but it actually breaks down into eight domains of care. And the way that we're going to approach this for the purpose of the discussion is we are going to go through each of the categories, the endorsement categories the way that we have done before. But under each category I'm going to ask that we consider each of the eight domains as one. Okay?

So, ideally, you will be voting on all eight at the same time.

If, however, you have concerns about one of the domains in any of the categories, then what we will do is we will pull that out and vote on it separately. Does that make sense to people? Okay.

So, for example, if we are voting on

evidence and somebody has concerns about the timely care items, we will pull that out and consider timely care separate from all the additional seven. Okay?

So the way I will do this is I will turn it -- I will first begin by asking if anybody would like one of the measures, one of the domains pulled out. If that's the case, we will pull that out. I will then ask the head of the work group, who I gather is going to be Deborah, to discuss first the remaining measures under consideration. We will vote on that. And then we will move to each domain that has been taken, moved out.

Does that work? And I think you'll get the hang of this as we go along.

Paul, did you have a question or is that left over from --

MEMBER TATUM: That's from pre-photo.

CHAIR MORRISON: Pre-photo, okay.

So we're going to start, we're going to start with evidence. I am just going to read the domain items and ask if anybody would like one of them pulled. They are communication; timely care; respect, emotional and religious support; symptom; training; rating of care; and willingness to recommend the hospice team.

So we will have -- would anybody like one of those pulled out for separate discussion?

(No response.)

CHAIR MORRISON: Okay. So we are going to consider all eight as one.

Deborah, it's all yours.

CHAIR WALDROP: I want to start by first reminding you, I know you've read this, but I just want to remind you that the numerator and denominator are just somewhat different than what we've looked at in previous measures.

The numerator is the percentage of those with the top box score or the most positive score on each of these measures. And the denominator is the number of respondents per item.

The exclusions to this are also

important to note that they have excluded patients who died within 48 hours of admission to hospice, when there was no care giver of record, when the care giver had asked not to be contacted, the care giver was institutionalized, or the care giver never saw any patient care. So, essentially, unavailable care givers who were excluded.

One of the important things that we noted is that there is a strong connection between the structure and processes of care that influence the outcome. There's an interdisciplinary assessment of care plan documentation. There's a grid, a literature grid that's provided that actually is very akin to qualifying exam grids that we use in my Ph.D. program in our -- at school.

And they, they focus on evidence in terms of interdisciplinary assessment, care plan documentation, timeliness of visits, the sensitivity of communication, how staff treats patients with dignity, how the patient is screened for needs and an in-depth assessment, an individualized care plan, and how the plan is monitored for goals, and also the relationship that's fostered with the patient's clergy and hospice staff provided training. So all these elements were looked at in terms of evidence.

The developer conducted -- this for me was really important for you to hear -- the developer conducted focus groups and individual interviews to gather these domains for assessment. And so it's grounded very solidly in what people explained what they need in terms of their experience with hospice.

Our recommendation was to pass this measure. And I'll stop there for now.

CHAIR MORRISON: Questions from the committee or others?

Okay, Amy. And I've got Tracy I know. Anybody?

Amy, go ahead.

MEMBER BERMAN: So just one additional comment. It's not listed under the exclusions, but the way in which this survey is done, we do not do this survey to those places that serve less than 50 people per year. And so just in understanding in terms of the evidence, you know, then for rural and frontier, you would likely not have evidence complete.

So I'm just clarifying those things that we would want to, to know, and that there is a potential for disparity in not measuring quality in those kinds of places.

CHAIR MORRISON: Great. Thanks. Thanks, Amy.

MEMBER BERMAN: We would have to ask the measure developers why it simply is that this survey that there's a cost attributed to it. I mean, you know, minimally $10,000 a year according to I think what was written in there. But there was a determination. And they would be able to speak to where that determination went from CMS to exclude surveying, you know, these smaller places.

MS. DEAN-WHITTAKER: We decided to

provide an exemption on the basis of size, meaning that there would be no implication for Medicare payments for a hospice that served fewer than 50 if they did not do the survey. They could do the survey if they wanted to but there is no Medicare -- no Medicare payment implication because they are exempt.

There were a couple of reasons for doing this. One is cost, as you mentioned. They are small; would this be too much for them?

The other is this: if you have a total of let's say 30 people in your hospice over a year and you are trying to survey them every month, you might have three or four people a month who die in your hospice. So if you send out three or four surveys and you get maybe one-third of the surveys you send out back, now you have one or two people at most a month, and you have maybe a total of 12 responses.

In terms of public reporting, 12 is such a small number that it's not reliable. It will jump up and down and, therefore, could give a very unfair rating to a hospice. So we don't, we will not publicly report the real small ones either.

So it was a question of quality of the data and the cost to the hospice.

However, if a hospice chose to do so, they are free to do the survey. They do not have to report it to us. They could use the results privately. They could report it to us, couldn't they?

DR. ANHANG PRICE: That's right. So if a hospice is not required to participate in the survey by CMS' rules, meaning that they had fewer than 50 survey-eligible decedents and care givers over the course of a year, if they choose to do so, hire a CMS authorized survey vendor to collect that data on their behalf, I think you need to submit that data to the CAHPS Hospice Survey data warehouse.

But, as Deborah mentioned, it would be basically impossible to publicly report it for a couple of reasons. One is that fewer than a certain number of responses we would be concerned about identifying a respondent, but also it would be too small a number to reliably reflect on the quality of care provided by the hospice.

MEMBER SCHROEPFER: And a follow-up to the developer, and that is about the exclusion of, in terms of the language, review there for the exclusion.

DR. ANHANG PRICE: Sorry, which exclusion are you referring to?

MEMBER SCHROEPFER: So it's in the denominator. Let me back up. Sorry about that. Has a language barrier, which basically would be that they don't speak English.

DR. ANHANG PRICE: Right. So the CAHPS Hospice Survey is available in a number of different languages. They're in English and Spanish and two versions of Chinese, and Vietnamese, Portuguese, Russian. And we're going to be adding additional languages over time.

So that exclusion refers to people who don't speak any of the above language that I just mentioned. And, again, we've, CMS has solicited input over the last couple of years, and continues to, about what additional languages would be useful to hospices to make sure that that exclusion from the denominator is minimized.

MEMBER SCHROEPFER: Great. Thank you.

CHAIR MORRISON: I'm going to jump in here guys because I had a feeling this is going to be a very contentious measure for many of us in the room. And I'd like us to remember to focus. We're really just talking about the evidence right now. And issues related to validity, reliability, sample don't fit into this and fit into the fact that we're really just focusing on the evidence.

So can we -- need to narrow the discussion here a little bit.

Wow, sorry. I didn't mean to have a chilling effect on the room. But I did want to sort of keep us -- we will get to these, we will get to these issues as we go.

So do I have other questions,

discussion about the evidence for this measure?

MEMBER LIND: Hi. This is Alice. Can I ask a question?

CHAIR MORRISON: Yes. Alice, go right ahead.

MEMBER LIND: Hi.

CHAIR MORRISON: I'm not going to embarrass Deborah further.

Go ahead, Alice.

MEMBER LIND: Can you explain -- I'm sorry if I missed it -- why is the rating for evidence just pass or no pass versus high, moderate, et cetera? I just kind of missed that explanation.

MS. JOHNSON: Yes, Alice. This is Karen.

This is an outcome measure. It is actually a patient-reported outcome measure. And for outcome measures we do not require the quantity, quality, consistency of the body of evidence.

So the requirements in terms of

evidence for a PRO-PM -- and just to be clear, we have eight PRO-PMs for patient-reported outcome-based performance measures that we're considering as one today. The evidence requirements are basically that there is at least one thing that the providers can do to affect the outcome. And since this is a PRO, we also want to have some comfort that there was patient input into the actual instrument itself and that patients find these kinds of questions meaningful.

So those are the two things you need to think about to determine pass or no pass for PRO-PM measures.

MEMBER LIND: Thank you.

CHAIR MORRISON: So if I don't see any other comments, I think, Jean-Luc, we'll go to a vote.

And, again, as Karen mentioned, this is a very straightforward vote. It's yea, pass; or nay, don't pass.

MR. TILLY: So to vote on evidence for 2651, select 1 for yes, and 2 for no.

And the results are 23 voting yes; and zero voting no. And so the measure passes evidence.

CHAIR MORRISON: Okay, guys, so we are going to move on to gaps and disparities. Again, I'm going to ask if there are any of the domains that people would specifically like pulled out: communication; timely care; respect; support; symptom help; hospice training; rating the hospice; and willingness to recommend. If there's any individual item that people would like pulled out -- or actually it's a domain, not an item?

(No response.)

CHAIR MORRISON: Seeing none, we will take this as a group. Deborah.

CHAIR WALDROP: Okay. So a couple things I want to remind you of first. That this, the multi-item measure scores were calculated as the average proportion that gave responses in the most positive categories. And the measure was adjusted for the mode of administration. So you heard Debra tell us that it was by mail only, by telephone or by both. And so it was adjusted in that way.

I wanted to direct your attention to the grid that's on screen because that gives you the mean and the standard deviation. And what we found is that there is in some cases very wide standard deviations or large standard deviations. And the means vary. So they're not 100 percent.

I think in our work group conversation we had talked about what do I do with a mean of 85? But it indicates that there's still opportunity for growth and for improvement, especially when we think about communication, we think about all of these elements. It's always important to get them as high as we can.

I want to also mention just briefly the issues around disparities because there were, there were disparities. And it wasn't entirely always in the direction that we might think. The direction of the disparities varied but there were racial disparities across the different domains.

And so I guess I would just close by saying that the spreadsheet of scores really indicate a range of scores and quite a lot of variability, which gives us opportunity for growth and improvement.

I'll just ask my fellow work group members if there's anything else you want to comment on around this reliability issue?

CHAIR MORRISON: Cindi, is that a work group comment or a non-work group comment?

MEMBER PURSLEY: Non-work group.

CHAIR MORRISON: Non. Okay. I'm just waiting. The floor is yours.

MEMBER PURSLEY: The way these answers read are percent always, percent usually, percent sometimes, percent never. And what we have found is that if you don't get the "percent always" then you don't get the top box.

So consequently, when you ask a question such as Did you feel the hospice team really cared about your loved one? and you're expecting a "percent always," I think that you're trying, unless you take "usually" and "always" together as top box, there are many people who just aren't going to say "always."

And we had 150 deaths last year. And we received 25 of our surveys back. So I have a small number. It's really in the overall scheme of things not really statistically valid but it's what I am being held against.

Consequently, if I get two "usuallys" out of those 25 --

CHAIR MORRISON: Cindi, I'm going to interrupt for a second. Is this related to a gap or disparities?

MEMBER PURSLEY: I think this is a gap. When you are a smaller hospice, unless you can combine those two top answers I just think that it really puts you in a difficult place.

CHAIR MORRISON: Actually, I think I'm going to table that one to the reliability question rather than --

MEMBER PURSLEY: Okay.

CHAIR MORRISON: -- rather than the gaps. Because I'm not sure, unless Karen tells me differently, that that really fits our NQF definition of gap or disparities for this one.

MS. JOHNSON: It is tricky. I think it best fits in a couple places: potentially reliability, maybe even validity. Reliability because that's how it's specked. Validity because if you feel like that's not really showing true quality. So it could fit either of those.

One could argue that it could fit under gap if that makes you disbelieve the numbers here and kind of not really think that these numbers are reflecting a true gap. But generally that's not the conversation that we have when we talk about gap.

CHAIR MORRISON: So can I hold that, Cindi, until validity or reliability and I'll come back to you?

MEMBER PURSLEY: Yes.

CHAIR MORRISON: Okay, great. Thanks.

Other thoughts, questions? And, again, I don't mean to -- this is, I knew this was going to be really complicated. It's a lot of issues. But when it gets to the voting on this, I want to be pretty clear about what we're voting on.

George.

MEMBER HANDZO: Yeah, I just want to say that I think one of the things that was just salient for me as I read this was that the disparities were not in a single direction, was particularly interesting because usually they all are. They are usually in a given direction. It means that the disparities are particularly complicated here and so the gap is particularly important.

CHAIR MORRISON: Do people feel comfortable for a vote? Okay.

So again we're voting on all eight domains in aggregate. So there will be one vote. And this is on the performance gap on disparities. And, again, we've got high, moderate, low and insufficient.

Right, Jean-Luc?

MR. TILLY: That is exactly right, yes.

CHAIR MORRISON: Excellent. Getting the hang of this.

MR. TILLY: Okay. It looks like we are missing just one vote in the room. Oh, thank you.

I have the results for performance gap are 6 voting high; 17 voting moderate; 0 voting low; 0 voting insufficient. The measure passes performance gap.

CHAIR MORRISON: Okay. We are on to reliability. I'm going to ask again, does anybody have one of the domains they would like to pull out, or would you like to look at them as an aggregate?

(No response.)

CHAIR MORRISON: Okay, we will look at them as an aggregate. I'm going to turn things over to Deborah. And I already have Cindi on my list.

CHAIR WALDROP: So it's important to make sure to remind you that the reliability of each of the elements was, or each of the measures was tested both at the data element level and also the measure score level. And consistency was measured using Cronbach's alpha and Pearson's correlations.

You can -- I want to turn your attention again to the screen, if I can ask Jean-Luc to move it down to the reliability testing grid so that you can see the consistency of these measures.

Hover, you know, just below point 7, which is an acceptable rating. And we found that this measure demonstrates moderate reliability in all the domains.

And let me again ask my work group colleagues if you have anything further to add about the reliability testing?

CHAIR MORRISON: I've got, Christine -- is this a work group or just a comment? It's a question.

Okay. So I'm going to go to Cindi and then I'm going to go to Christine.

MEMBER PURSLEY: Okay. To add on to my previous comments, what happens here -- and I used the Did the hospice team really care about my loved one? -- we now educate our staff, we teach to the test. When you go in and you're dealing with a family you say "because I care about your mom." And so it's very defeating, I feel, that questions are posed and only those top, only the "percent always" is going to be the acceptable answer.

I don't think it's a true evaluation. And my idea of what caring looks like may be very difference from a patient and family. And I think that we're trying to impose upon families what caring looks like. And it's very different and it's very personal and it's very subjective. And, consequently, I think adding the two top boxes, especially when you're a smaller hospice, is important.

CHAIR MORRISON: Christine.

MEMBER RITCHIE: So, in some of our previous measures we basically said that the threshold for reliability was point 7. And, you know, granted some of these are close, but point 6 I would argue is not close. I just wanted to sort of get clarity about whether or not we're changing our consensus about what the threshold is.

CHAIR MORRISON: Christine, before we move forward are you -- and I'm coming back to my question at the beginning -- are you asking that specific domains be pulled out because of those estimates and should be discussed separately or not?

MEMBER RITCHIE: Well, I'm asking are we comfortable, is NQF comfortable with, you know, in the previous staff reports you said the minimum standard was point 7. So I just want clarity about whether or not the minimum standard is something that we are still sort of keeping at point 7? That's really, it's a question, not pulling domain.

MS. JOHNSON: So really NQF does not have specific thresholds. We give that rule of thumb just to let you put that in some kind of context. Many people do feel that point 7 is kind of the minimum that they'll consider. Others are not that strict. Others may say, depending on what you're doing we want to see something like a point 85 or even higher.

So different people have different levels of comfort with reliability statistics. So apologies if that felt like it was an NQF threshold, that it had to hit the point 7. It's not a actual threshold, it's just a contextual rule of thumb.

CHAIR MORRISON: Amy.

MEMBER SANDERS: So I'm not sure if this is a request to pull out some domains, but I'm wondering if somebody could explain why rating of hospice and willingness to recommend the hospice under data element are listed as not applicable?

CHAIR MORRISON: I'm sorry, those are a, that's a, it's a -- I'm sorry, Deborah, you can answer. I was going to. It's a yes/no. It's not a -- it's a single item. It's a single item so the Cronbach's alpha doesn't apply.

Cindi and then Tracy.

MEMBER PURSLEY: The rating of hospice is 0 to 10, and so you have to give it a rating. And only 9 and 10 are utilized.

CHAIR MORRISON: Correct. Or, well, it is a single rating.

Tracy. Please. That's okay.

MEMBER SCHROEPFER: So looking at going back to Christine's question about the reliability, and if I look at the getting emotional and religious report, point 66, so items not necessarily hanging well together. But I'm wondering about the combination, why you would put or why emotional and spiritual has been put together?

In some ways they're different and someone may not want religious support but want emotional support. Or I just am just wondering about that. And I think the reliability speaks to my concern.

MS. JOHNSON: I'm going to ask RAND to comment on that, please.

DR. ANHANG PRICE: Sure. Happy to do so.

So we did take a look at the emotional support question separately from the one about spiritual and religious support, and found that the addition of all three questions together, so the two emotional support questions and one religious support question actually improved the Cronbach's alpha. So it seemed to hang together as a construct for our respondents. And that's why that's reflected there.

I think also as a practical matter, as we're considering the number of measures to be developed from one survey, thinking about one measure that does hang well together that reflects -- that sort of reduces the total number of measures available for possible public reporting is also a consideration.

CHAIR MORRISON: Yes, Michelle. And then George.

MEMBER CAUGHEY: So going back to Cindi's concern, you know, and we do hospital CAHPS and home health CAHPS and so on, I had that same concern to these which is sort of the way your, your auto repair shop prepares you for the survey. And so in hospitals you're prohibited by Medicare from teaching to the test. But it's human nature to want to get a good score.

And so it does, the actual reliability of the survey itself I think is what we're, we're bringing up, you know, not so much the reliability of the evidence. So maybe I'm not understanding the process completely, but that's where I was coming from.

CHAIR MORRISON: George and then let me try and clarify. George.

MEMBER HANDZO: Yeah, on the spirituality and --- this has been a bone of contention. Press Ganey has done the same thing historically, as many know. And I don't know the right answer. I'm appreciative of the data which suggests that it actually enhances the Cronbach's alpha which is probably the first data I've ever seen that actually gets to this question.

But it's not a question simply for this, it's a much broader question of scope of practice and how it fits and it's well beyond the scope of what we're talking about here, in my opinion.

CHAIR MORRISON: Other comments?

(No response.)

CHAIR MORRISON: So let me try and, you know, focus this back.

So we are being asked as a committee to look at the reliability of this specific measure which is comprised of eight domains. And within each of those domains some have multiple items.

So we are being asked to look at two things. One is, within each of the items, okay -- or, sorry, within each of the domains do the items hang together reasonably well so that they are essentially measuring one concept? And that is the Cronbach's alpha measure.

So and it ranges from alpha point 84, which suggests that the communication items hang together really, really well, to a point 60 -- Am I right measure? I hope so. -- around timely care where they probably don't hang together quite as well, and the emotional and religious support is somewhere in the middle. And what you have heard from the developer is they have looked to see what happens when they take one measure out and put one measure in. Okay? And they have done that.

The second piece we're looking at is the interclass correlation or the overall reliability when you look at this domain across different settings. Okay? There, again, you know the accepted value, quote unquote, is about point 7 -- above point 70. And we see ICCs that go from a low of point 61, which is the treating family member with respect, all the way up to a point 78.

What I don't think we can focus on here, quite honestly, given the number of people and how this is going out, is our own anecdotal experiences with this test. Okay? And our own anecdotal experiences with that.

That being said, if people are concerned about "coaching," that may, and I say may be reflected in the relatively poor reliability of the timely care, that some hospices are doing something, and some hospices maybe do something else. I don't know what that is but there is a difference.

So I think in terms of focusing, again coming back to this discussion around reliability, I think we really need to focus on those two items which are within the domains to the items, saying do the individual items hang together well? And I think more importantly, within those domains is the reliability one that's tested across settings acceptable?

Does that help? Okay.

Sorry. And I see Rebecca dying to get

in as the developer, so.

MEMBER MOSS: Actually you raise good questions, Sean.

So when we're looking at the Cronbach's alpha are we actually comparing the responses within a hospice? Is that what you're -- are you comparing within a hospice or are you comparing between hospices? You see how that's different?

DR. ANHANG PRICE: So the Cronbach's alpha calculation is based on the entire data set. It looks how individual respondents respond to every question on the survey and how the responses correlate to one another.

The ICC and then that estimated reliability at 200 completed surveys is a measure of the degree to which the domain shown here differentiates between the performance of one hospice and the next.

Does that answer the question?

And I did want to briefly respond, if it's okay, to how we came up with the top box scoring methodology as opposed to some other means of scoring these data. Most commonly it would be a linear mean score between 0 and 100 because, of course, we recognize the concern that you expressed.

First of all, the quality assurance guidelines by the CAHPS Hospice Survey, similar to the HCAHPS guidelines, indicate that hospice staff are not supposed to do coaching around the specific answers to the questions. We recognize that that's a concern, number one.

But, number two, we took a look at the distribution of top box scores versus linear mean scores to see whether the reliability of the measures was better using one type of scoring versus the other, and determined that top box is actually the preferred approach for being able to distinguish between hospices.

And second of all, I looked at top box versus linear mean scoring in terms of its acceptability and comprehensibility to the public. Because in anticipation of public reporting, we know that top box scores tend to be more digestible by consumers, and prior research has shown that.

And so that's I think what drove CMS' decision to collect top box versus a linear mean score.

CHAIR MORRISON: Professor Berman.

MEMBER BERMAN: Sorry. Just going back to Cindi's point, one question is, are you looking to measure the greatness of a place or are you looking to identify the poor performers? Because the notion of looking at I guess the, you know, those that are usually performing well or always performing well might tell you something different than identifying only the top box.

So I just want to hear a little bit about the thinking there, what you're trying to really measure?

MS. DEAN-WHITTAKER: What we are trying to do in terms of public reporting is provide data that is easy for the public to understand and that is not -- and that is meaningful. So we don't want to make our criteria too easy to meet, and yet we don't want to make them too hard to meet. We are interested in making information available to the public.

I think that's only a partial response. But I don't think it's fair to say we're interested in identifying the poor performers in particular. Because if you're not top box, let's say you don't -- if your score is not a top box score, does that make you a poor performer? While if your score is mostly in the "usual" then you might be more of an average performer.

On the other hand, if you have relatively low top box score, that then means that you are getting fewer big pluses than the guys who are doing really well.

But our first idea is to give the public something they can understand.

Am I responding to you?

CHAIR MORRISON: And I -- yeah, and I just have a clarifying question for Karen and staff because I want to be clear in terms of our deliberations. Are we talking about this as the measure that's been proposed or are we talking about how CMS reports the measure? Which are very different.

It's CMS' decision to report top box in public reporting. That's not how the measure is placed in front of us. And I, again, don't want us to get confused around a conversation about what we're discussing.

MS. JOHNSON: I think I'm a little bit confused, Sean, because my understanding is what is before us is actually what CMS will be putting forward as public reporting, as far as you know. So I think they're the same.

CHAIR MORRISON: CMS is reporting the top box and collapsing. Is that what's before us, is what I'm asking?

MS. JOHNSON: I believe CMS will be reporting top box. And top box is what is what is in front of you. Am I correct?

MS. DEAN-WHITTAKER: We anticipate

reporting top box. That could change. But right now that is our current plan.

MS. JOHNSON: But Sean's point is well taken because you have to put what's in front of you, that's what you're evaluating, knowing that when it gets out in the world, in the wild as we say sometimes, things can change.

MS. DEAN-WHITTAKER: The other thing is that we're also concerned about getting topped out measures. And these measures often score quite high, as you may have noticed. So that if you were to combine the top two, you might find that you're bumping up against 100 percent a lot of the time.

So that, that is also a concern to us. But you don't want the measures to be topped out because we know that -- well, what we've seen is that we are getting very favorable reports much of the time.

Would you care to comment at all, Rebecca?

DR. ANHANG PRICE: I think that covers

the landscape.

I think one other important piece to note is that hospices are contracting with a survey vendor and get back detailed reports often from their survey vendor upon their request that allow them to identify which survey items are causing them the most problems, help them to identify those for quality improvement as well.

But that might be a little different than what you were suggesting, which is at a national scale being able to identify, you know, problems, "problems" with this.

CHAIR MORRISON: I've got Paul, I've got Debra. And, Amy, are you still up? Okay.

MEMBER TATUM: I heard -- well, first let me just say thank you. These measures are so important from my perspective as a hospice doctor to help my team get better, as a palliative care team leader to know which hospices to partner with, but also as a family member. So thank you. This is important.

My question relates to the question

about "always." And being one of the Midwesterners here, I'm just wondering because I don't think Midwesterners are going to say, you know, "always" because everything is about average. If I can quote -- yeah, maybe just a little better than average but we're not going to be at the extreme.

So I just wonder if that is a potential threat regionally at all?

DR. ANHANG PRICE: That's an interesting question. I'm not sure whether the "percent always" in the Midwest has been explicitly investigated. Although I do know that in other CAHPS efforts there has been a question raised about whether it's appropriate to case mix adjust for the regions of the country. And the decision ultimately has been not to do so, in part because you don't want to accidentally obscure true differences in quality that exist across the country.

And so you will see when you talk about risk adjustment for this, for these measures, that region of the country is not included.

CHAIR MORRISON: Deborah.

CHAIR WALDROP: For the good of the order, I would like to just put out there, not a motion perhaps but a question for you about whether we want to pull out treating family member with respect and getting help for symptoms, because of their score level reliability? Would people feel better if we looked at them separately?

CHAIR MORRISON: Yes?

MEMBER SCHROEPFER: Yes, and I also want to go back to getting emotional and religious support. And I agree with George, at least it's here. And that's a step forward. And I appreciate that because most of the time things are very medically focused. So that's great.

But at the same time, because we put the spiritual with the emotional and it raises reliability, doesn't necessarily mean that we're getting what we need. And there are a lot of items, I mean there are other questions --

CHAIR MORRISON: Tracy, can I ask, I think that's more of a -- if it's not about the reliability, let's table that to validity. Because that's really about are you measuring what you think you're measuring. Okay? As opposed to the reliability which is if you say you're going to take it out, the reliability is going to go down. At least statistically that's what the measure is.

MEMBER SCHROEPFER: I'll hold it then.

CHAIR MORRISON: Hold it. Thanks.

MS. JOHNSON: And, Sean, it might be helpful before there's a pull out or not, maybe, Rebecca or Debra, you can elaborate just a little bit on your decision to do the N equals 200 and the implications of that. That might be helpful as well.

MS. DEAN-WHITTAKER: RAND actually suggested that to us. And I think that it would probably be best to let them explain why. But we agreed with them.

DR. ANHANG PRICE: Sure thing.

So in selecting which estimated reliability threshold to display here, there's a tension between recognizing that there are many hospices across the country that are relatively small where achieving a high number of completed surveys will be difficult, while at the same recognizing, that as Deborah mentioned, while there is some variation in these measures -- and we saw that earlier today -- many of them, many hospices do perform very well on them. And reliability is really driven by the number of completed surveys and the variability in the measure across hospices, since you're trying to differentiate between hospice performance.

So we selected the N equals 200 threshold to balance those two concerns, to establish a threshold that we thought would be achievable for a fair number of hospices, especially for pooling over four quarters, as Deborah mentioned, while at the same time recognizing that we wouldn't want to set it at, say, N equals 300, which is which it is for HCAHPS, for example, because that would be just too many for many of the hospices nationwide.

CHAIR MORRISON: So I'm going to come back to Deborah who put a suggestion on the table to pull two measures for separate discussion or separate voting. And I just want to see where people are.

And A) if after that, Deborah, you still want to do that then B) where the committee is on that.

Is that the right way to go, Karen?

MS. JOHNSON: Uh-huh.

CHAIR MORRISON: Okay. Christine?

MEMBER RITCHIE: It would influence my vote.

CHAIR MORRISON: So I'm going to put a motion on the table that we pull a -- what did I say -- treating families with respect, and getting help for symptoms, we will consider each of them separately. And then we will consider the rest as a group.

PARTICIPANT: Second.

CHAIR MORRISON: Second.

Getting timely -- Deborah, help me out, which one were you.

Yeah, no, it's treating families with respect and help for symptoms, which were the two offered.

Yeah, Linda? Microphone.

MEMBER SCHWIMMER: Would it also be the same cut-off, potential cut-off for the validity testing? Because those end up being different numbers for different --

CHAIR MORRISON: We're going to go to validity testing next.

MEMBER SCHWIMMER: Right. But I'm just wondering if we vote to do certain ones in a group for certain things, when we hit the next category you're going to have different groups?

CHAIR MORRISON: We are.

MEMBER SCHWIMMER: Okay.

CHAIR MORRISON: We are. We are. I realize this is why we are taking it carefully.

So I've got a motion on the table first before I get to Woody. So, the motion is to pull these two out, consider them --

MEMBER MOSS: Point of clarification?

CHAIR MORRISON: Yeah, point of clarification -- yes.

MEMBER MOSS: So actually I have the advantage of just sitting next to the measure developers and I can lean over and whisper to them. And I asked, really, isn't the data in which you end up with the lower scores for treating family member with respect and getting help for symptoms, isn't it the same data set, it's just more of a variation between hospices? Which Rebecca said yes.

So I'm not sure there's a point. Just a point of information. I'm not sure there's a point in separating them out; we're dealing with the same data.

CHAIR MORRISON: We're dealing with the same data but we're also dealing with how the domains differ across them. And I think that is the -- that is the problem of a complex -- not a complex, a composite measure. Okay? Yes, it would be different if we were -- but it is -- that's how I've been told to do it, Woody. Sorry, Rebecca.

So, again, so I've got a motion on the floor that's going to pull these two measures out. We'll vote on those separately and then we will vote on the rest together.

All in favor?

(Show of hands.)

CHAIR MORRISON: Anybody opposed?

So I'm going to need to see hands. All in favor?

(Show of hands.)

CHAIR MORRISON: Okay, so the motion carries.

So let us start then, let's do the easy part first, let's do, let's vote on all of the measures except treating family members with respect and getting help for symptoms. We are voting on the reliability.

Jean-Luc.

MR. TILLY: Yes, that's right. So select 1 for high; 2 for moderate; 3 for low; and 4 for insufficient.

So the results are 1 voting high; 20 voting moderate; 2 voting low; 0 voting insufficient. That cluster of measures passes reliability.

CHAIR MORRISON: So now we're going to focus specifically on the treating family member with respect. I feel like we've had a pretty robust discussion about these. But I will ask if there's any more discussion that needs to happen before we go to a vote. And, George?

MEMBER HANDZO: It's a question. I mean what's the effect, I'm trying to understand if we say that six are reliable and two are not, I mean what is that? Because normally if we say they're not -- they don't pass reliability, the measure goes down. I mean do we, I mean I guess I'm asking to what extent do these necessarily hang together?

I can see the concern. And I'm okay with that. I just want to make sure we understand what the implications or can there be any implications of one up and one down?

MS. JOHNSON: So from the NQF perspective, again we allowed these measures to come in as one submission for convenience because there are so many things that are similar, but you really have eight separate measures in front of you. So two or one or five can go down and the other ones would not.

So in terms of how NQF would look at it, that it would be just like any other eight separate measures that you would be looking at.

CHAIR MORRISON: So is that, everybody clear on that? Okay.

So we are now going to vote on the reliability for the treating family member with respect.

Jean-Luc.

MR. TILLY: Yes, that's right. Vote on this one measure, treating family member with respect, so it's 1 for high; 2 for moderate; 3 for low; and 4 for insufficient.

MS. ROILAND: We're just waiting for one more vote over the phone. Sorry for the delay.

MR. TILLY: I'm sorry, Bob. Could you text or alternately email me for a vote on this one?

Okay, so the votes are 0 voting high; 10 voting moderate; 10 voting low; and 2 voting insufficient. So the testing -- the results are in the gray zone for treating family with respect.

CHAIR MORRISON: Okay. So then we are now going to turn to the getting help for symptoms measure. And, Jean-Luc.

MR. TILLY: So vote on reliability for getting help for symptoms. Select 1 for high; 2 for moderate; 3 for low; and 4 for insufficient.

I'm sorry. We're going to have to re-vote it looks like.

CHAIR MORRISON: Yeah, because we're

not in Chicago where you vote early and vote often.

MR. TILLY: Hang on for a second. I need to reset the voting and then we'll be able to try again.

Okay, so for reliability on getting help for symptoms, select 1 for high; 2 for moderate; 3 for low; and 4 for insufficient.

The results are 0 voting high; 14 voting moderate; 7 voting low; and 2 voting insufficient. So I believe the measure passes on reliability.

CHAIR MORRISON: Okay. So we're going to move on to validity and another active discussion. And, again, before I turn things over to Deborah, are there any one of the eight domains that people would like pulled out to discuss separately?

(No response.)

CHAIR MORRISON: Deborah, the floor is yours.

CHAIR WALDROP: Okay. I'm going to

walk you through the validity testing. And the developers did empirical testing in two ways. First, they examined the relationship between the six multiple item, multiple item measures and the global rating measures. And I want to point out that at first when the work group met there was no data about the global measure on recommending hospice in the work group. So the developers took that back and then gave us subsequent feedback.

So in the measure evaluation sheet that you see, the tracked changes are the new data that we have.

And so what they, second, did was Pearson correlations between the agency level multi-items and looking at the association between them.

And if you look on screen, Jean-Luc has put up the associations with the global rating measure of hospice, each of them individual multi-item scores; and then the association with the willingness to recommend measure.

In terms of threats to validity, there are exclusions that I mentioned in the beginning, and those should be noted: again, people under 18, those still alive, those who died within 48 hours, and those who essentially whose care giver was unavailable.

And then, finally, in terms of validity, I did want to mention that there was risk assessment completed statistically. And the work group found moderate -- high, actually high validity on all measures. It was insufficient in terms of the willingness to recommend. But then with the subsequent data that was provided by the developers, that's then shifted to high.

And I'll stop there.

CHAIR MORRISON: I know that I cut somebody off at some point about talking about validity. I think, Tracy, was it you? You want to come back?

MEMBER SCHROEPFER: I think at this point I'm going to say, I'm going to say what I think -- I just want to say that for the portion we're talking about what is missing and what we need to look at, rather than address this particular.

CHAIR MORRISON: That would be great. So we'll save it for our discussion about gaps. Brilliant. Okay.

Paul?

MEMBER TATUM: Thank you. Again I'm excited about these measures. I believe the national response rate is 32 percent on this.

And I'm wondering about a mission-based hospice dealing with a, perhaps a low socioeconomic status, low literacy rate as their mission, and what happens when you have a hospice that has an extraordinarily low response rate, how that influences things? I thinking, I think if they're smaller, you know, we have a 50 cut-off. But a low response rate could get us to only having a small number of surveys.

DR. ANHANG PRICE: Sure. So perhaps to rephrase the question to be sure that we understand. Is the question what happens in the instance of a small hospice, particularly one with perhaps an underserved population that's more likely to have a lower response rate, when they have very few completed surveys in the course of a quarter or year? Is that the question?

So I think ultimately CMS is in the process of making -- thinking about how they publicly report these data. And there will be a minimum threshold below which it won't be possible to publicly report for some of the reasons we've already talked about, both identifiability and reliability for comparison with other hospices. Those hospices will still receive reports from their vendors that indicate how they're doing on each of the questions to which respondents provided responses. And they can use those for the purpose of quality improvement.

In terms of inclusion in an accountability program for public reporting it is more challenging because, because of the reasons that we talked about from preventing those sorts of responses from being included in public reporting for any case for performance initiatives that would be introduced at a later time.

I will say that there's considerable variation in response rates according to mode of administration. So most hospices across the country are using the mail only mode because it is the least expensive mode. But there is a telephone only option and a mixed mode that uses both mail and telephone follow-up. That one is more expensive to use, so it might be unaffordable for some hospices, but does produce much higher response rates than average, so in the 40 percent. So that is an option that is available for hospices if they are interested and can afford it.

CHAIR MORRISON: Amy.

MS. DEAN-WHITTAKER: May I say something?

CHAIR MORRISON: Sure.

MS. DEAN-WHITTAKER: One of the problems that we face, not only on this project but also others, is the desire of providers to be in the public reporting mix and be on the website as publicly reported. And we have really sort of pulling things on us.

One, we want to give public reporting to as wide a number of providers as we can. On the other hand, we also don't want to publicly report something that would be unstable or unreliable. So we are constantly worrying about, well, you know, should we go ahead and report something, even though you are beginning to have relatively small sample sizes and, therefore, unstable results.

That is, by the way, one reason we report four quarters of data, not just the most recent data. We're trying to smooth out things.

So that is a constant problem that we face. And it does have to do often with the smaller providers who want to be included but for whom the data may actually not be very good.

The other thing I would say is that CMS does accept the data, it does include it in data sets that we make available, and it does not impact whether or not the hospice is given a full payment by CMS. CMS' payment system has to do with Did you report the data? not What does the data say?

So I'm hoping that -- but certainly, as Rebecca says, the problem is if you have low literacy and non-English speaking, then can you find someone who would be able to do it on the phone at a price you can afford? And if you're a small hospice, is that something that is going to make it hard for you to do?

We are aware of it.

CHAIR MORRISON: Amy.

MEMBER SANDERS: So I apologize in advance because I have multiple questions. The first is whether any consideration has been given to response bias as a threat to validity? The people who are most likely to fill out the 47-

question survey and send it back are going to be those who are going to rank either very, very high or very, very low. And I think this is a, response bias is a potential issue with all of these surveys.

My second question is sort of related. And that's whether there has been any thought to improving I think validity by coming up with either a shortened version, doing some sort of, you know, item analysis to see do you really need all 47 questions. And if any assessments -- or actually I guess my, a more basic question is What is the reading level of the questionnaire? I mean is it at a sixth grade reading level?

So if it's a tenth grade then your response rates may go up if the reading level were lowered, which is really hard to do but may be worth it.

CHAIR MORRISON: Well, I'm going to ask you guys if you want to address the -- if you can address the response rate issue. And, again, I think, you know, the issue -- I hear what you're saying, Amy, but we can't rewrite the instrument for them. So I think just tackling the response rate and not issues around changing the instrument. We have to deal with what's in front of us, the response bias, not response rate.

DR. ANHANG PRICE: Sure thing.

So to the degree that it's possible with the data we have we look at response bias, the hypothesis that we have about more and less positive ratings is difficult to investigate with only the data that we have, obviously, would be to have some sort of gold standard group that represented a broader pool of possible respondents to know that for sure. But as you mentioned, you know, that's a challenge of any survey of the future.

We did, between the field test and the national implementation of the survey, shorten the survey substantially to try to, to try to streamline it. We have found in other past efforts that reducing the length of a survey by a handful of questions did not substantially improve response rate. So we don't really have reason to believe that that would improve our response rates here. In fact, the family evaluation of hospice care survey that many hospices across the country were using prior to the CAHPS Hospice Survey are substantially longer.

And so we were hoping that by landing on a survey of this length that covers all of the many domains of interest that we've talked about today plus the necessary demographic information about the respondent and the decedent, that we've sort of landed in a place that makes it a usable survey, and so we're going to see, you know, hundreds of thousands of responses that we're analyzing in the data set here that recognize the concern that you express is one that is across many patient surveys.

MS. DEAN-WHITTAKER: In terms of reading level, we did check that early on. And the CAHPS Consortium was concerned about that. And we worked to reduce it. I think we would like to reduce it further.

I don't remember now what it was, but I do remember clearly it was higher than we wanted. It was closer to tenth grade than it was to sixth. And we wanted to reduce it. And we did rewrite questions and cognitively test questions in order to reduce the reading level issue.

In terms of a shorter survey, there was one thing about this survey that makes it a little longer than we would have liked, and that is that we collect some demographic information on the patient and some on the respondent so that you -- we shortened each section but we do have questions about both because we thought there would be an interest in analyzing both. And that does tend to contribute to a higher number of questions than you might otherwise have observed.

CHAIR MORRISON: Paul and then I think I am going to close unless people have burning issues around validity rather than feasibility.

MEMBER TATUM: A potential threat to

validity, and not enough to stop us moving forward but might be worth tracking I think, what about the patient whose care is in the nursing home? And how do we know if the respondent is ranking just the hospice or are they actually ranking the staff of the nursing home?

MS. DEAN-WHITTAKER: That's one of the questions we ask only of nursing home -- of care givers of nursing home patients. We explicitly ask them that. And that's something that's only asked of nursing home patient care givers as to whether or not they were being given different information by the nursing home and by the staff of the hospice.

And there was a second question there, two of them, and I can't come up with both. But we do ask explicitly about that.

CHAIR MORRISON: Are people okay if we go to a vote? Okay.

So we're going to vote on the composites, yep, all together. Yep, all together, Jean-Luc. And this is on the validity, just to orient people to where we still are.

MR. TILLY: So to vote on all the measures for validity select 1 for high; 2 for moderate; 3 for low; and 4 for insufficient.

The results are 6 voting high; 14 voting moderate; 3 voting low; and 0 voting insufficient. The measure is passed for validity.

CHAIR MORRISON: Well done, guys. All right, onwards and upwards, or downwards as the case may be. We're going to move to feasibility. We've already had some comments about feasibility which I'll summarize when we move forward. And, Deb, all to you.

CHAIR WALDROP: Just a couple more items to put in the feasibility category.

First of all I want to make sure you recall that hospice, that CMS has done a dry run in early 2015. And this survey has been in continuous use. So they have data about its feasibility.

For me, one of the issues that I

raised in the work group was that the data can be collected in three different ways: by mail, as I mentioned, phone or in a mixed sort of interview and mailed capacity. And I just, I think this just comes from my researcher hat, which is is that equivalent data, and does that give us performance measures that are the same across all modes of administration? Just a question for consideration.

And then one of the other issues that was raised on our work group call was that there is no information on the expected cost to facilities. And for smaller hospices and for rural hospice perhaps, it may be an onerous cost for the use of this survey and also the reviewer's time, or rather the medical reviewer's time in terms of contracting with a certified survey vendor if they need to.

And I think I'll stop there. Anything else from my fellow work group colleagues?

CHAIR MORRISON: Deb, do you want me to now turn that the measure developers? I've got two questions there. One is the differences across the three in terms of feasibility and what that means? And then the second was the issue about low resource hospices, yes.

CHAIR WALDROP: Yes.

MS. DEAN-WHITTAKER: We did do testing by mode. There was an entire mode experiment. I'm going to ask Rebecca to maybe describe in detail. But we are planning on adjusting by mode. So that any publicly reported results will have that adjustment. But perhaps Rebecca would care to give more detail.

DR. ANHANG PRICE: Sure. So just briefly, the experiment that Debra mentioned was a randomized experiment within approximately 50 hospices across the country such that the surveys administered within the given hospice were split between mail only, telephone only, and mixed mode. And that helps to differentiate any effect that might happen from which hospices would be more likely to choose mail only versus mixed mode, for example. And it's a randomized experiment.

And the results of that experiment are being used, were used to create a set of adjustments that allow us to fairly compare across the three modes of administration for each of the items on the survey.

CHAIR MORRISON: Michelle.

MEMBER CAUGHEY: So has Medicare considered additional dollars to support hospices in reporting both the hospice item set and the performance of the CAHPS Survey?

MS. DEAN-WHITTAKER: Your question is has Medicare considered providing additional money? As far as I am aware, no. But I cannot speak to the hospice item set at all. But with respect to the Hospice CAHPS Survey, that discussion has not occurred in my -- that I am aware of.

MEMBER CAUGHEY: Just a follow-up question just in a public health sense that the marginal hospice agencies, even small additional dollars may have impact on the availability of these services. I don't know if that's outside the scope. But it seems that feasibility, as we rate that, I think we need to bring up that issue.

CHAIR MORRISON: Christine.

MEMBER RITCHIE: So I might be missing this, but under the committee pre-evaluation comments there was a comment around a difference in response rate by educational level of the care giver. And I just couldn't find that data. I just want to --

CHAIR MORRISON: So, Christine, is this a question about whether --

MEMBER RITCHIE: Fifty-four? Thank you, Amy. Page 54, if you didn't hear that.

CHAIR MORRISON: So is the question here the feasibility of collecting from people of low --

MEMBER RITCHIE: Yes.

CHAIR MORRISON: -- socioeconomic status?

MEMBER RITCHIE: Yes.

CHAIR MORRISON: Okay. So I guess I'll turn that over to the measure developers.

MS. DEAN-WHITTAKER: Well, I guess I would have to say initially -- and I will ask Rebecca to comment too -- that we do have a problem with this but it's a problem that addresses all surveys, the home health, the hospital, and others as well. I am not aware of but would be willing to certainly be enlightened as to whether or not there would be a particular issue with hospice.

But I am aware that we do have the issue in general with surveys that rely on literacy and with low literacy groups.

But perhaps did you have any comment you'd like to add?

MEMBER RITCHIE: I was going to express the same response, which is that it is of course concerning to see higher rates in non-response among groups that we would really like to hear from in a survey like this. Unfortunately it's a problem that affects every similar survey as well.

We're fortunate to have these different modes of administration which could help with that a bit, again if the hospice elects that mode of administration and can pay for it.

CHAIR MORRISON: Christine, are you up, down? You're down.

Any last thoughts on feasibility before we go to a vote?

(No response.)

CHAIR MORRISON: Jean-Luc.

MEMBER PURSLEY: One more question to Debra. And that is you mentioned earlier that there was a study that was done with a shorter version of the survey versus a longer version of the survey. And I was just wondering what the sample size was for that and how many hospices were involved in the assessment of the shorter survey.

MS. DEAN-WHITTAKER: Well, the shorter survey is the one that became the final survey. The longer survey was a field test. And what we did with the field test is we basically gave them the kitchen sink. Everything we thought we might want to include we had in there.

And the field test was done with a smaller number of hospices. Now I -- do you know offhand, Rebecca, how many there were?

DR. ANHANG PRICE: Sure thing.

MEMBER RITCHIE: It's irrelevant if this is the shorter survey.

MS. DEAN-WHITTAKER: This is the shorter of the two.

MEMBER RITCHIE: Never mind. Yeah, it's irrelevant.

DR. ANHANG PRICE: Well, to one point it might be relevant which is that that longer survey, which is field tested among 33 hospice programs with about 1,200 respondents had the length of the survey range between about 68 items to 72 items, depending on which setting of care the decedent had been in. And the response rate for that field test was higher than what we see in national implementation, even for the parallel mode of administration mixed mode.

Which is why I think that intuitively we think that a longer survey means people are less likely to respond. But we haven't found that to be the case.

CHAIR MORRISON: Jean-Luc.

Cindi, is this a?

MEMBER PURSLEY: Just a quick comment that our veterans' families get a much longer survey.

CHAIR MORRISON: Jean-Luc.

MR. TILLY: Okay. So to vote on feasibility for the cluster of eight measures, select 1 for high; 2 for moderate; 3 for low; and 4 for insufficient.

The results are 0 voting high; 17 voting moderate; 6 voting low; and 0 voting insufficient. The measure passes feasibility, measures pass feasibility.

CHAIR MORRISON: Okay. We are on to the final session of the final measure of the final day. And, fortunately, I think this will be relatively straightforward.

Deborah, usability.

CHAIR WALDROP: So that's my key to be brief.

Okay, so just a couple thoughts on usability and use. First of all, the measure is not yet publicly reported but there is a plan to create a compare website which I think could be very useful.

And then the only other issue I wanted to raise with the committee, we had a conversation with the developers at the work group meeting, but that's the notion of unintended consequences. So bereaved care givers will be receiving the survey two months after the death of a loved one. And the only -- and this again is from my research hat, the one that I have to wear to the IRB -- which is you're going to make people cry. Are you going to make people cry? Is this going to be a problem for people?

And so we talked about what would that be like to receive a survey two months after your loved one has died. And we decided that the benefits outweigh the burden of that.

And what I understood from our conversation was that to date there have been no responses that people said, Why did I get this survey? or any harmful way. And they return any distressed care givers back to the bereavement program of the originating hospice.

So those are my thoughts on feasibility and use.

CHAIR MORRISON: And, Deborah, you did want to point out that this is already in use in the hospice Quality Reporting Program, right? As usability?

CHAIR WALDROP: Yes.

CHAIR MORRISON: She did.

Woody, go ahead.

MEMBER MOSS: Yeah, I just have a question for those of you who are in the hospice setting. So when people complete this survey do you ever get calls to your bereavement coordinators? And are you aware of any negative consequences from that?

CHAIR MORRISON: Go ahead.

MEMBER CASS: Yeah. I think that we do, we certainly do. And I think actually these are good because it identifies people that really need extra support. And while sometimes we may be distressed by the results in a specific survey, it does enlighten us that we need, we need to be out there taking care of this individual.

And again is that bias about do people report more when they are in distress? But either way, I think it's positive for us to be alerted to the need for psychosocial interventions.

CHAIR MORRISON: Amy.

MEMBER SANDERS: I think that the issue of getting 47 questions about your loved one who recently passed away probably has a lot to do with the relatively low response rate. People just look at it, think "I can't deal with it," and put it in the trash. I know that's what I did.

CHAIR MORRISON: Cindi.

MEMBER PURSLEY: I concur with the two previous comments.

CHAIR MORRISON: And, again, I want to focus us on this is whether it's actually in use and usability, rather than feasibility which is what we just dealt with.

Amy Berman.

MEMBER BERMAN: So related to the usability and use, just putting out there again that this is not going to small hospices, so this is the kind of exclusion to use and usability. And understanding all of the existing constraints and respecting those constraints, one other thing to think about would be aggregating data over a longer period of time in rural and frontier areas so that we would have some sense, and the public would have benefit of understanding, you know, the relative quality of the local hospice.

CHAIR MORRISON: Thank you. Other thoughts, comments?

(No response.)

CHAIR MORRISON: Okay. We're going to go to the vote on usability. Jean-Luc.

MR. TILLY: To vote on usability and use for all eight measures, select 1 for high; 2 for moderate; 3 for low; and 4 for insufficient information.

The results are 8 voting high; 13 voting moderate; 2 voting low; and 0 voting insufficient information. The measure passes usability and use -- measures.

CHAIR MORRISON: Okay, guys, I was wrong. We do have one more vote. Sorry.

So this one is on the overall measure. And I just want to be very clear about what you're voting for. You are voting for the overall composite measure for only seven domains. Okay? Because we put into the gray zone the -- sorry -- treating family member with respect. So that means that we cannot vote on it as an overall endorsement.

So you are voting on seven measures

for endorsement: the communication; hospice care training; timely care; emotional and religious support; and getting help with symptoms. Did I get them all? No. And the overall rating; and the willingness to recommend.

Okay, does that make sense to people? No puzzled looks?

And they're in front of you. Even better. Hospice team information; timely care; getting emotional and religious support; help with symptoms; hospice training; rating of the hospice; and willingness to recommend, Rachel points out to me. So that is what you're voting on.

MS. ROILAND: Paul, did you have a question?

CHAIR MORRISON: I'm sorry. Paul.

MEMBER TATUM: Maybe it's just a brief comment that I don't envy Karen the job of explaining our rationale of dropping one measure and not the other. And I didn't know if we needed to comment further on that because from a statistics standpoint I don't really understand what you did, but.

MS. JOHNSON: It really is one of these little funky NQF processes. So basically because the one measure that you guys pulled out landed in that gray zone of consensus not reached, our rules are we don't ask you to do that final vote for that one.

We will ask you to re-vote on that one on the post-comment call. And there will be a final vote on that one at that time.

CHAIR MORRISON: Paul, anything that follows NQF process she can explain beautifully, so don't worry about that.

All right, so yea or nay, folks, up or down.

MR. TILLY: To answer the question for the seven measures under consideration, does the measure meet NQF criteria for endorsement? So 1 for yes; 2 for no.

The results are 22 voting yes; 1 voting no. The seven measures are recommended for endorsement.

CHAIR MORRISON: Congratulations, folks. We are done with all of the measures.

Just before we go to lunch, and you guys have really, really deserved it, I need to open up the phones for public comment and then turn to the room.

So, Operator, if you could open up the phones for public comment. And just to remind people, public comment is on the events that happened this morning, not events that happened yesterday that you might have missed.

OPERATOR: Thank you. At this time to make a public comment please press star one on your telephone keypad.

At this time there are no public comments.

CHAIR MORRISON: Fantastic.

So then let me turn to the back of the room for public comment. And could I ask you to come up to the miC, if you have one or two.

DR. SPENCE: Okay. All right, thank

you.

First of all, I have a huge amount of empathy and admiration for the team that put this together.

CHAIR MORRISON: Carol, I'm sorry, can you introduce yourself?

DR. SPENCE: Oh, I'm so sorry. I was here yesterday. Okay. All right.

Carol Spence, National Hospice and Palliative Care Organization.

I think it's referred to in the submissions briefly, but we had the precursor to the CAHPS Survey, the Family Evaluation of Hospice Care, which is why I have so much admiration and respect for what the CAHPS team and RAND have produced.

I just want to make one comment specific to the response bias issue. And forgive me, I'm not 100 percent familiar with everything that goes into the file that is submitted to the vendors. I know there is decedent information.

One of the things that we did with the

demographic information that was collected was, in our reports of course we reported it out, but we pointed out to hospices that they should compare the demographic information of the respondents to their patient census, which they, they could easily do, to look at who was not responding. So, you know, diagnosis in particular group, but age for a number of reasons.

Again, our survey was not for accountability as this one is, but it was for quality improvement. So for hospices to look at were there care givers -- was there a group of care givers who were not responding? You know, were they an older group, a particular ethnic group, and that meant they had to do something about their survey that they, you know, that they could. But also to look at if they have a huge particular, you know, cancer population but it was the debenture people who are returning the survey, et cetera, et cetera.

So I think this is not perfect but it

is one way to look at response bias and in a way that could help the hospices, you know, know who they're reaching, who those patients are whose care givers are returning the survey and who they're not is a piece of the puzzle.

MS. SINCLAIR: Hello. Stacie Sinclair from the Center to Advance Palliative Care. I just wanted to thank you again for your thoughtful work this morning.

As the committee begins or prepares for its discussion on measurement gaps in the field this afternoon, we just wanted to highlight that there remains a gap in quality measurement or quality reporting for small hospices. Data, including a recent article from Melissa Aldridge demonstrates that they tend to perform poorly on quality metrics.

And as you established during this morning's discussion, CAHPS may not be the appropriate measure due to the high cost burden on providers and the low validity in response rate. Therefore, this was just something that we wanted to urge you to keep in mind for this afternoon's discussion.

Thank you.

MR. JEFFRIES: Hi, Sean. Craig Jeffries. I am with Compassus. We're a national provider of hospice and palliative care.

And I just wanted to reinforce I think comments that were made both on some of the preliminary calls and here today. I'm specifically thinking of the 0216, 0215, but it's applicable to others. But just to reinforce that some of these measures deserve cost setting consideration. They're very good measures. They could be utilized by other physician specialties.

So I know that's not really in the scope of what you're doing today but I think if the record could indicate that this is a topic that came up and important for further consideration.

Thank you.

CHAIR MORRISON: Well, I think now -- So I think what I'm hearing from Karen is I think what we're going to suggest is a short working lunch so people can get out of here, rather than a regular lunch. So why don't we take 10 minutes to get food and then come back and we can start on the agenda for this afternoon.

And, George, I see a hand.

MEMBER HANDZO: Sorry. I haven't gotten this card thing down at all.

CHAIR MORRISON: No worry.

MEMBER HANDZO: Are going to make any attempt or can there be some attempt to kind of coordinate rides to airports?

CHAIR MORRISON: Rachel.

MEMBER HANDZO: Yeah, I didn't want to pick on Rachel right out of the box. But I thought that's where it was going.

MS. ROILAND: No, that's okay.

So when we adjourn the meeting -- and thank you, Tracy, she's made the suggestion that if folks are heading straight to the airport right after the meeting we would just like you to sort of meet under the clock over there and you can try to coordinate cabs together.

And, also, if you are wanting to try to take the Metro to the airport we're very close to McPherson Square. And the Blue Line train there will take you directly to the airport as well. So that's another option.

CHAIR MORRISON: That goes to National. The Blue Line goes to National.

MS. ROILAND: Sorry, yes. Yes. I apologize.

CHAIR MORRISON: Dulles is a taxi.

Let's break for lunch rather than getting into Washington transit discussions. Thank you.

(Whereupon, the above-entitled matter went off the record at 12:35 p.m. and resumed at 12:52 p.m.)

A-F-T-E-R-N-O-O-N S-E-S-S-I-O-N

(12:52 p.m.)

CHAIR MORRISON: So we're going to get restarted. This is actually the fun part of the day and a half. And as soon as Karen comes back, we will get going. Actually, Rachel will take over. Rachel?

MS. ROILAND: All right. Hi, everybody. Just while you're eating, I'm actually going to walk around and ask you to take a little piece of paper out of this pink cup, so we can divvy up the two- and three-year terms. So it's just random happenstance about which one you get, and that will be what we'll go with moving forward.

MS. JOHNSON: So for Bob and Alice on the phone, we are sending around the cup for people to do the random selection of terms. And, Bob and Alice, we will figure out how to randomly select for you. So stay tuned.

Okay. It looks like pretty much everybody has taken their piece of paper from our cup and our hat. Just a reminder that you will have an option, once your terms are up, if you want to re-up for another term, that would be an option open to you. So two years from now, we'll start talking to a few of you about whether you're interested in that option.

So with that -- yes?

MS. ROILAND: So what I'll ask you to do, just for the sake of time, if you could write your name on the little slip of piece of paper that you took and just drop it off with me before you leave today, I'd really appreciate it. And then I'll randomly select for, Jean-Luc and I will randomly select for Bob and Alice and Robert. So just so we're all clear about that. Thank you.

MS. JOHNSON: Great. Okay. So this part of our discussion is actually probably going to an interesting and fun part for you guys, and it's not going to be as hard of work as what you've done in the last day and a half, so that's a good thing.

What we want to do is have a discussion about framework and gaps. So let me put it into a little bit of context for you. Yesterday, I showed you a draft framework. I mentioned a framework that was done in 2006 by predecessor groups, so we have that one. You may know of other frameworks that might work for, again, a measurement framework, a way to think about what measures we have, what measures we need. So we want to talk about that a little bit.

We also want to talk about what are the gaps in measurement, and I think one of the things we have to -- and you guys can guide this -- do we need to split out end of life versus palliative or is it okay to talk about everything together? You guys will help us understand that, in terms of gaps.

I threw up a few questions here on the screen just to consider. We don't have to go through these in order. How should the draft measurement framework be modified? So, again, with that, maybe we go back to the original one. Maybe you know of something completely different, so that's fine.

What are the gaps? What are our measurement priorities in terms of, so not just talking about what the gaps are but, you know, if we had to tackle something sooner, rather than later, what would be the ones that would need to be done first? So that's what I meant by priorities.

And to some extent, are you aware of other measurement efforts? So, you know, if things are already in the works that you know about, let us know. We don't want people going off and spinning wheels and reinventing wheels if there's something already going on, and maybe you guys know about this. And, quite frankly, maybe you're doing some innovative things in your own shops, and maybe those need to come to NQF. So that's what I'm getting at there.

So this is going to be a bit of a freeform conversation. So who wants to start us out? It looks like Paul.

MEMBER TATUM: I'm so glad this picture just came up because this is what I wanted to address. And I'm here partly thanks to the American Geriatric Society so putting my geriatrician hat on. And, Karl, you might speak to this from the long-term care side of things.

One of the things missing on settings of care is the assisted living facility community. And Joanne Lynn on, I believe, the Diane Rehm Show a year or two called assisted livings the Wild, Wild West in terms of, you know, oversight and regulation and quality measures in that domain. And so I think we should think about adding that on to our settings of care, and I think it's a critical area for us to think about what is quality there.

MS. JOHNSON: Okay. Woody?

MEMBER MOSS: So, actually, Christine and Arif can speak to this even more knowledgeably than me, but the American Academy of Hospice and Palliative Medicine has a Measure

What Matters Most to patients, and I think some of those measures would be very good ones for us to look at with the idea that people have criticized measures sometimes as being convenience measures, what's easy to measure but what's important to measure. So I just, there are ten of those in the Measure What Matters Most and we could look at them.

MS. JOHNSON: Right. Actually, a few of those are NQF-endorsed measures that you looked at this time around, but some of them, you're right, they're not. Amy?

MEMBER SANDERS: So I have two questions, one of which I think is probably very specific and the other one is a little bit more wide-ranging. The first one, the more specific one, at least in my head, is whether the change by CMS effective at the beginning of this calendar year to begin reimbursing for advanced care planning discussions with patients is something that is currently addressed in any sort of measure anywhere. Maybe that's not as specific as I thought it was.

And then also what the sort of group feels about the utility of disease-specific measures or syndrome-specific measures. A lot of measures are focused on cancer, but people die from a lot of other things. So, you know, if somebody is dying from COPD or, you know, my personal area of interest, which is dementia, where the care-planning can go for years, if not even, you know, longer than a decade and how that sort of changes the way that measures would be developed.

I know the American Academy of Neurology does have a measure currently in development, or in update, related to advanced care-planning discussions for patients with dementia.

MS. JOHNSON: Does anybody want to respond to Amy's questions? I don't think that was directed to me necessarily, right? Christine? Okay. So you weren't -- I'm just asking if you were responding to Amy or --

MEMBER RITCHIE: It's related to what Amy Sanders said, which is -- and we already addressed this a little bit over the past two days, which is that we do have a lot of measures that are focused on specific conditions and not multiple chronic conditions, and this is becoming increasingly a point of concern, as I now am engaged in population health at my institution and seeing a lot of things being applied to the inappropriate population because they just happen to have that one condition in the mix.

MS. JOHNSON: Okay. Amy Berman?

MEMBER BERMAN: So I guess two things. One is around the notion of palliative care in general. Today, we can't really measure whether somebody got a palliative care consult. We have challenges getting basic information, which would then be able to tell us against claims data whether or not doing those things has an outcome around value. And we're all moving toward value.

I think we need to understand what is specialty palliative care, when that has been applied, versus when primary palliative care may be offered, and we need to look at both and whether or not, as we create competence in a broader workforce to deliver palliative care, and the purpose of their appointment is to deliver that palliative care, whether they're successful in doing it, versus when experts are brought to bear and whether or not -- when they can't manage that care, then the field of palliative care is deployed and what is the value proposition of that.

So we're constantly conflicted. As a matter of fact, I've heard that some people measure, for example, referrals to palliative care. Why do they measure referrals? Because they can't measure whether or not they got a palliative care visit. This is kind of absurd when we talk about palliative care as being one of the major areas we want to measure, and we can't measure even the most basic data there.

The other thing, I guess I'm going to go to the center of the circle, and I could talk about a lot of things, but I'm going to talk about the family. And patient and family are at the center. If this were a pediatric guidelines meeting, we would have talked quite a bit around family aspects. There is going to be a report coming out by the National Academy of Medicine around family caregiving in older adults. Some of those recommendations may be very helpful as you develop out the work because the family caregiving issues are big and largely unaddressed. We don't know who the caregiver is. It's not identified in the record. We don't ask whether somebody is willing to do something. We make assumptions, and the system falls apart if we don't do a good job.

So the family caregiver aspect I think is one of those great opportunities for NQF to address.

MS. JOHNSON: Arif?

MEMBER KAMAL: Yes. As Amy so brilliantly and eloquently said, some of these things -- one of them, and Christine and I and several of us have thought about this, is the denominator issue in palliative care, that as change agents for healthcare, which, in a lot of ways, palliative care, as a field and as a discipline, has been anointed the change agent in a lot of different ways. Fix the 30-day readmission rate, who's going to do that? Well, it's not the cardiologist, right? It's the palliative care clinicians that are often tapped to fix this problem for us.

So if we are willing to embrace this idea of change agents, that means it requires making an impact above and beyond the patients we actually see face-to-face, right? So there's what do we do as a specialty? But if we ask ourselves the question who within NQF or across the healthcare quality environment is developing measures for serious illness and critical illness that addresses these domains, that may fit in other specialties per se that we never see, are others picking up the torch and doing that, or is that really the responsibility of our discipline?

In addition, in terms of specific domains that I think we're missing, from some work that we've done on systematic reviews of quality measures, you know, the domain of cultural and social aspects of care, I mean, it's just two big empty boxes and spiritual -- other than do a spiritual assessment. So there are important gaps that exist.

In terms of new domains, we know that financial toxicity in multiple different surveys, at least in cancer patients, is either number two or number three of their concerns. And number one and number two tend to be sort of the future, and how am I and my family going to sort of deal with this experience issue? Number two seems to be symptoms, and number three, not that far behind, is financial toxicity. So I wonder if we should bring that into our wheelhouse of things we feel comfortable addressing.

The other thing is when people ask us what we do and we say the patient caregiver is the unit of care for us, I look at this and I say, well, we don't have an imperative or marching orders to address anything related to the caregiver, which I think has, ultimately, fiduciary and reimbursement implications down the road as well, in terms of how I spend my time with a patient. I bill the patient, yet I'm supposed to focus on a caregiver, yet there are no quality measures that say what I'm supposed to do and how often I'm supposed to do it.

And then, lastly, some have talked about the triple aim everybody knows, but some have written actually in the family medicine literature about the quadruple aim around this concept of preserving our workforce. Many know that there is a burgeoning area of work around resiliency training in our field. We estimate that, one, that our burnout rate in our field is higher than any other field that we know of, one; two, that we expect to lose 50 percent of our workforce in the next ten years with the primary reason, other than retirement, being burnout, as stated in our survey; and that, three, the proliferation of resilience programs and other things within palliative care has been slow. It's slow across all of healthcare, but I think it's an important thing here. I think last night at dinner we talked about a structural or process measure to say what we do is tough, and we need programs or something in place to address that.

MS. JOHNSON: Okay, great. Karl, I think on this side.

MEMBER STEINBERG: So something -- I think there's a little bit of a gap as far as functional measures, and I don't know if functional should be one of the domains of care, but I mean we have physical, and I guess functional impairment sort of would go under that.

But, I mean, that impacts so heavily on things like prognosis, and so I think that's something that -- and of course, there are measurements, there are measures for functional status like on the MDS and so on. And I guess they're going to be improved coming up in the near future, but as far as treatments that people are getting and how functionally impaired they are, let's say if you're getting chemo and those kinds of things.

And I think there is a difference between palliative care and end-of-life care, but -- there might be some measures that apply to one and not the other. But I think they're similar enough that it's reasonable. Us sitting around the table, we're dealing with both.

MS. JOHNSON: Okay. Sean?

CHAIR MORRISON: I apologize that I have to leave early because I gather this is going to be a fascinating discussion. So just a couple of comments before I go. In thinking within the measurement framework, when I look at this measurement framework that has end-of-life care, palliative care, and bereavement care, what it strikes me a bit is this is a very healthcare-specific model and that patients and families don't classify themselves as being "at the end of life," and we are terrible at doing that. And palliative care assumes that that's a specialty-driven care.

And what I would much rather see is this framework be around serious illness because that would bring in geriatrics, it brings in pediatrics. It's non-specialist care, and that would encompass all of this. And part of the problem is that we've never been actually able to define that denominator. But I think we are getting much better at it. Amy and Christine just recently published a very good paper that could identify a population of patients with serious illness with very specific attributes that could be relatively easily obtained from administrative data if the necessary changes were made.

And I think, Karen, within that context, then you have both setting-specific, stage-specific, specialty-specific measures that would apply. But I think we really have to get outside of this healthcare or medical box of how we think about the population at risk.

And then bereavement care, quite honestly then, as Amy said, comes down onto the family framework, rather than the patient framework, unless -- I haven't figured out how to have seances yet, but George will work on that with me. But I think that that fits in in terms of the family care, so that's the first thing.

The second thing which has been ignored which, again, is a very, very high priority, at least for me, is to start rethinking about the quality metrics that we see for this patient population around patient safety. We have narrowly focused patient safety on acts. We've narrowly focused patient safety on infection. But quite honestly, I think pain belongs in the patient safety area. I think the poor transitions belong under patient safety, and I think there are a wealth of measures that apply to our patients and families that really should be under that much broader rubric and shift out of "the serious illness quality metric" because they really are adverse outcomes that have strong implications for the safety of this population of patients. And I think, from my perspective, we have to start advocating for that gap within the patient safety rubric or framework. So I will thank you.

MS. JOHNSON: Thanks. George, yours is up.

MEMBER HANDZO: Thank you. Two things, one on the framework and then on the gaps. But I've already confessed my involvement with NCP, but I really like the eight domains of NCP, and I think it's well-established now and well-vetted and all of that, and I think that, for me, is a very helpful framework to see this. So just that.

And so within that, even going back, it looks like, and Tracy and others have talked about this, where, obviously, if you take even four domains, if you take Cicely Saunders and the original four, you're heavy on the physical, not that there's not a lot to do. I'm not trying to say that. But the social and the spiritual and emotional and spiritual are virtually absent.

And so things like -- I mean, we have in spiritual care a validated screening tool or more or less validated screening tool for spiritual distress. It's a three-question tool. So we don't know -- to Amy Berman's point, we don't know what the real prevalence of spiritual distress is in any healthcare population, including this one.

So screening and then the way we've done it, the kind of screening, assessment, treatment continuum, I mean, the beliefs and values is great, but it needs to be paired, like dyspnea and pain, with a so what, so you have a discussion: so what? There needs to be a way to move on from that like the rest, and we need to move into those areas. And both for emotional and spiritual, I think, are both aligned there.

So, I mean, I think I would start with a follow-up to beliefs and values, and I'd start with a basic kind of where we are with everything else, let's screen for it and find out what's out there and then validate the literature from there.

But it's a -- I always laugh when people say, can we do a gap analysis on spiritual care? Because it's a gap. It's all a gap. Pick your place, it doesn't matter.

MS. JOHNSON: Debra?

MEMBER WIEGAND: Thanks. I just wanted to comment that it seems like a population that's missing from measurement is pediatric and neonatal palliative care and end-of-life care.

MS. JOHNSON: I've kind of lost track. Over here, Gregg? Christine?

MEMBER VANDEKIEFT: So I completely agree with everything Amy and others have said about having the patient and family at the center and making that our focus, but what I'm going to say almost goes counter to that, which is one of the things that we've struggled with, is how to extract meaningful data in the era of the electronic health record, and I don't know how much rating or evaluation or measurement of various vendors or products has been done and whether something of that nature would actually be beneficial to where you could actually look at the Epics or the MEDITECHs and see what can we extract, how can we work them, and grade them and evaluate them in our own way? Maybe that's being done; I don't know. But it just occurred to me as something that's such a great challenge in the field. It might move us forward.

MS. JOHNSON: John, is that a -- okay. Christine?

MEMBER RITCHIE: So just as an add on to what was said by Arif and Sean around safety and financial toxicity is treatment burden and treatment-related harm.

MS. JOHNSON: And what was that last word? I'm sorry. Treatment-related harm. Got it. Let's see. Tracy?

MEMBER SCHROEPFER: So two things that I'd like to talk about. One is culture. And I think in terms of this, so I work a lot with tribes, Amish, different populations in

Wisconsin, and work closely with them around end of life, and what comes up a lot is that using hospice, palliative care, hospitals is very difficult for them because their cultures are not honored; their ways of life are not honored. Self-determination, familial determination, most of the time or a lot of the time for some of the cultures, is more correct. And so feeling like -- and what a lot of the tribes that I've done qualitative interviews with, et cetera, feel that they can't ask questions of doctors or nurses or even social workers because they feel like people think they're stupid and dumb, and part of that has to do with the lack of time that's spent with them and also recognizing that their language, like, for example, with the Hmong, we have a high Hmong population, and I've been working with them for about seven years, and there's not a word for cancer in Hmong. It's not that simple. Chemo, radiation.

So feeling like we have a lot of work to do there if we're going to look at quality at end of life and with serious illness.

I think the other thing is environment. We don't think a lot about environment. I just want to give you an example, and then I promise I won't talk a lot. The example is, with one of the tribes, hospice is pretty -- the reservation goes very deep, and where people live is deep in the reservation. And so, you know, the elders often talk about, yes, we start with hospice, but we don't stick with hospice, and the reason is because we're so far in, we get scared, the families do, that, should something come up, that nobody could get there quick enough to relieve the pain or whatever. So they'll start with hospice, but what they'll end up doing is going in the hospital. And we've talked about tele-medicine and different things.

But in terms of the hospital, we have a hospital in Wisconsin that being aware that the elders most likely will end up in the hospital, the issues for this particular tribe are the need to burn sage at the end of life. Okay. That's not good because you could blow the hospital up, right? Oxygen tanks and stuff, yes. And they understand that. The need to chant, the need to drum, the need to have family. And family is so different: for many populations it's not the immediate family; your 20th cousin is family. So where are the rooms large enough? Windows. Several of the tribes, the need to open the windows so the spirit can leave. So this hospital actually created a room away from oxygen and insulated it so the drumming, et cetera.

So I know there's so much to do, but we often say why don't people use hospice or hospice facilities or hospitals, et cetera, and part of it is that the environment for them --

And then the last thing is, and this kind of gets to the spiritual, is for doctors, and this is down the line, thinking about how we measure a more integrative care in terms of, for the Hmong is the shaman and the need for the shaman to work with the doctor. That's really important. Curandero for certain Latino populations, a traditional medicine man for some of the tribes. And what I've heard is there was one tribe up north, Bad River, where the doctor there honored the fact that when an elder got cancer and had tumors, they first had to work with the traditional medicine man to spiritually be ready for the chemo and the radiation. This was the only doctor that would wait and not say things to the patient about you're crazy; that's going to take two weeks, and your tumors.

So just thinking that there's so much I could go on and on and on about the importance of culture. But I think it is something that we mention, but we don't do a lot with, and it really does end up that people feel very alienated.

My last thing I'll say is something so simple as one of the Hmong leaders said to me one day, we had been working together for a number of years, and he said, "So now I can ask you this question because you won't think I'm dumb," and so Feluck said to me, he said, "Tracy, when we go to UW Hospital, why do we only get students?" He said, "Why the Hmong just get students?" and I explained to him it's a teaching hospital and that everybody gets students. Nobody had ever explained that, but he also had been afraid to ask it because it would just be another stupid question by a Hmong person. And that's his language, not mine.

So I just want us to also bear in mind the importance of culture when we think about this in moving forward because it's embedded in, we talk about pain, we talk about symptoms, sometimes when we're measuring things we're not measuring them correctly because culture is not being taken into consideration, even down to pain charts where an elder told me you can have all those faces you want; we'll always choose the middle because it's stoic, and that's who we are.

So that's it. I'll shut up now.

MS. JOHNSON: Cleanne?

MEMBER CASS: I'm just curious about

process. Do we develop a suggestion for a measure, and then a measure developer picks it, up, or how does this work? We can sit here and have wonderful ideas, so should we be structuring our thoughts a little bit more around what they're interested in, or how does that work?

MS. JOHNSON: Ideally, yes, you guys would mention and kind of come to some conclusion about the priorities, and somebody would pick it up. That doesn't always happen, but I do think they are paying at least some attention, knowing that different developers have different goals, depending on the developer, depending on who's funding the development, et cetera. So I think, at least right now, the best we can do is get things on the table and get them out there.

That said, and I don't know, Marcia, if we need to talk anything about the work that NQF is doing in the prioritization. Is that something that would fit in here?

MS. WILSON: It's a great question, and I'll just make a brief comment about NQF has been going through some strategic planning exercises, and one of the things we're looking at is prioritization of gaps, identifying gaps in a more organized fashion. Another activity I would mention that's going on is something, the NQF measure incubator, which is a new enterprise for us, relatively new, where, as you know, NQF does not develop measures, but we know a lot of people who do. And so we've taken on a role, this NQF incubator project, and there are others in the room I know who could speak to this, as well, where we're trying to facilitate or coordinate people who have measure ideas, measure data, funding for measures, and measure developers, who have the technical expertise that people can come forward and say we're interested in developing this measure, and we help coordinate those relationships and put people in touch. It's a relatively new program, but we have a couple of measures who are going through this process right now. We hope it's going to work. One of the measures is a patient-reported outcome for COPD, and another, we're also working on a contract, the Robert Wood Johnson Foundation has funded PatientsLikeMe, if you're familiar with that platform. It is a web-based patient-sharing data platform to look if that data perhaps could be used to develop patient-reported outcome measures.

And one thing I will say, we've had a lot of interest in this incubator project, and most of the interest has been in developing patient-reported outcome measures. So stay tuned for there. But we're hoping that might facilitate some measure development more quickly, more efficiently. We hope. It remains to be seen. But also looking at our gaps because we get gaps from you all, we get gaps from all of our committees, how can we present those gaps in a more organized way so people can say, okay, I'm starting to see the common theme here; I'm starting to see the priorities. So it's very much on our radar.

MS. JOHNSON: And I would add to that

we may have a little bit of time before 2:00 to talk about next steps beyond just this endorsement project. We call them off-cycle activities. So one possibility for an off-cycle activity might be to put some more meat around these bones and do a little bit more focused job than what we're able to do in an hour around the table. This is right now kind of the brainstorming thing. It's the brain dump.

So that's one option that we could potentially go for.

MEMBER CASS: I feel like if we're going to get excited about something, we want to make sure it's going to go somewhere. That should try to focus us, help us.

MS. JOHNSON: I have kind of lost track of who said what, so I'm just going to kind of go back and forth this way. So I think Laura.

MEMBER PORTER: Thank you. What I want to bring up is something that we talked about at dinner last night also. It seems to me that when we refer to palliative care in the group, we're talking about end-of-life care and that there really isn't a differentiation between palliative care and end-of-life care. And I know, as a stage 4 cancer survivor, I think that if I had had palliative care early in the process, I would have been spared a lot of the horrendous side effects that I went through.

And so my issue is that all of the measures that we looked at were basically end-of-life measures and hospice measures, but are we going to look at palliative care just as palliative care, or do we, like somebody suggested last night, need to change what we call it? I mean, I don't know if that's our role, but, I mean, it's kind of -- that's just my concern because I thought when I came here that it would be clear that there was a difference, and I was kind of disappointed that I didn't find a difference between palliative care and hospice, that they were used interchangeably.

MS. JOHNSON: Okay. Amy Sanders?

MEMBER SANDERS: So a couple of things

once again. I think that what is needed is a series of sort of knowledge and attitude surveys. I think that out in the world what is meant by palliative care, hospice care is not well defined. People often conflate the terms, I think perhaps to a greater degree than is sort of current within the borders of the hospital. I think we're beginning maybe to separate those two terms, but that's new. And so knowledge, attitudes, understanding, and obviously it needs not just to be about the physical and the medical but the cultural, what are the barriers to people accepting the offer of help and assistance in the form of palliative or hospice care?

And I think that we need to survey ourselves, as well. I think that we don't have a universal understanding of the nomenclature that we all use, and when we use those terms, we may mean one thing, but the person or group to whom we're speaking understands a different term. So I think maybe really taking things back to first principles, dealing with nomenclature, would be important but probably some sense of what actually the understanding abroad in the world is would be a necessary first step.

And I would also like to compliment whoever made this diagram that's currently up. I think it was somebody on this group who sort of put this diagram together, and I yesterday in my study immediately copied it down. And I think it's a really, really helpful diagram, so kudos to whoever did that.

MS. JOHNSON: Thanks, Amy. I'm going to skip over to Deborah.

CHAIR WALDROP: Thank you. So I have a couple of disparate contributions hopefully. First of all, I'm looking at the diagram, to tag on to what Amy said, and I think, in terms of domains of care, one of the pieces that's really missing is decision-making, and so decision-making not just around end-of-life decisions but across the course of an illness trajectory, and I would say across the course of a specific illness trajectory. So it's very different when you have end-stage renal disease or COPD than cancer, and I think we need to think about the decisions along the course of illnesses and help people with symptom exacerbations and what the end stages are going to look like in different disease trajectories. That's thought number one.

Thought number two is also in terms of settings of care, it's big boxes: it's inpatient, outpatient, home, hospice, and skilled nursing. Assisted living, as Paul says, needs to be there, but so does emergency medicine. I think the marriage of emergency medicine and the crisis that families find themselves in when they don't know what dying looks like, the call to 911 that maybe is the right thing to do. Maybe ED is where the person needs to go, but maybe it isn't. And if we could meet people where they are, I think there's a real sort of emerging literature and emerging study of palliative care in the emergency department, but I would like to take it into the field and think about it there.

And I think I'll stop there. Thank

you.

MS. JOHNSON: All right. Let's see. Ruth? Oh, sorry, Karl, was that a response to Deborah's --

MEMBER STEINBERG: No, I was just, I don't mean to be out of order, but I just want to say it's been a real honor to be here with all you guys, and I look forward to working with you more. Thanks.

MS. JOHNSON: Thank you, Karl.

MEMBER LIND: Hi, this is Alice. Can I just get in the queue?

MS. JOHNSON: Yes, why don't you go ahead, Alice, and then we'll go to Ruth.

MEMBER LIND: Sorry, Ruth. So I just have a couple of real quick thoughts. One is just about triaging some of these measures by particularly under-served populations. So one would be getting better data and a measure about people with serious mental illness and their being offered and then their take-up use of hospice and palliative care.

Another which is even more problematic, I think is people with substance abuse disorder history, and similarly, their being offered and their take-up use of palliative and hospice care. And so those are two that I think we just need to measure, kind of utilization measures.

Another kind of butter topic is coverage for palliative care, especially with private insurance and then also with Medicaid, which varies from state to state. And it becomes kind of problematic for people who are on both Medicare and Medicaid at times to have those two benefits coordinated, and so we trip across this in Duals Committee from time to time, knowing what the total cost of care is and whether people are being referred appropriately if they have both Medicare and Medicaid.

On a similar notion, most of the really excellent demonstrations that go on in Medicare right now or in Medicare/Medicaid demonstrations exclude people on hospice, precisely because the costs are kind of self-contained, and so it's hard to see cost different outcome when people are already on hospice at the time that the demonstration starts. And so it's something that needs to be looked at for demonstrations just to raise the question, should new demonstrations be offered through the Innovation Center that target this population in a specific way?

So I think those are my main thoughts, and I thank you very much for letting me participate by phone.

MS. JOHNSON: Thank you, Alice. Ruth?

MEMBER MACINTOSH: Thank you. Most of my question was answered about the process, but one thing I just want to have more clarity on is yesterday, a lot of times we were bringing up things about the specifications, and we learned quickly, can't change them. But there was recommendations, and who's going to be the voice from here to where those need to go?

MS. JOHNSON: Just so you know, when

we go through and write the report, those kind of comments come out, and we actually put those in the gap discussion. So if you guys mentioned yesterday, we need a measure here or if you would change this measure this would help, that will work its way to the gaps listing, as well.

MEMBER MACINTOSH: Thank you.

MS. JOHNSON: Michelle?

MEMBER CAUGHEY: Oh, thank you. I was -- I have sort of this framework in my head, and so I started to write it down. And I appreciate other comments.

So you start out with a population of patients who you want to serve in a palliative sense or in a hospice sense, and I think Alice's comments were right on. Are we actually serving the patients who need that care, right? Do we identify who needs it and who doesn't? So that's sort of the population.

Then you think the ideal outcome measure, in my mind, is have you then, having identified patients who are in some kind of distress, have you actually reduced that stress? So that would be your outcome measure, right? Measuring, you know, the level of distress before you intervene versus after you intervene is something actually we're going to attempt, but I think it's not -- so in the current world, we're sort of stuck either patient-reported outcomes of distress, like how well in the HCAHPS, did you -- they're very indirect, right? Or process measures, right? Which we know, process measures we hope move us along. They're not the end. We need them now because we don't have measures that, in whatever domain, that would be the true outcome that we would be looking for in either an individual or in a population of patients.

So sometimes we have sort of intermediate outcomes. I'm not quite sure where -- I mean, we've talked a little bit about that, but I'm not sure exactly what that is. So, anyway, that's sort of a framework that I'm dealing with and I think might help improve the conversation.

The population issue that Alice brought up I think is really important because there are patients who need this care who aren't getting it, and they're in all these places because the resources are so limited. So how we actually decide who gets it, the algorithms there, and how we then measure that, I don't know. Anyway, just a thought.

MS. JOHNSON: Okay, thank you. I'm looking at the clock. There's a couple of other things that I desperately want to get to before we go to public comment, so I'm going to let everybody have a really quick word, if it's at all possible. So Paul?

MEMBER TATUM: Very fast. I was thinking about methodologies where you vote after a big discussion like this, and I'd just say if I only had one star, I'd hop onto Amy Berman's. How we measure what palliative is is just so critically important. If I got five stars, she gets four, Arif gets one burnout. Just such critical, critical issues for our field. Just to kind of tease that back into this discussion. I think those are really crisis issues for us.

MS. JOHNSON: Tracy, is yours still up? Is that a new -- okay. Amy?

MEMBER SANDERS: So I just want to add one more, and, Gregg, I'm going to respond to what you said and also to, I guess, what Sean said before he left. I'm going to look at this with a serious illness frame, and let me also state that the National Academy of Medicine, they are using that terminology and that framing. They're going to be doing a serious illness roundtable, so that would be consistent with how they're viewing.

But care concordance, treatment concordant with people's values and preferences, that is a challenging area. That's kind of the center, and it's the area we kind of look away from because it's just too hard to measure.

So I want to point out that Mary Tinetti and Caroline Blaum are doing work called Patient Priority Care, and it is work that is in partnership with the Patient Centered Outcomes Research Institute. They're working within a large ACO across the state of Connecticut. They are eliciting goals, and then they are working with the major medical societies, the ACC, ACP, ABIM, to then translate out what that actually means. And so while that may seem to be kind of not possible, it not only is possible, but there are going to be measures developed out in this area. So I would say that that is strongly an area that we can go to looking in. And in the interest of full disclosure, we're funding that.

The Society of Academic Emergency Medicine, as we speak, is having their consensus conference on just the topic that you're suggesting, which is around how do we do shared decision-making, advanced care planning in the emergency room. That's where I came from before coming here.

CMS, if they are on the line, the question around primary and specialty palliative care, this is an issue that only they can address. How do we get access to that data means that they need to change the way in which data is reported so that they can note this. This is a fundamental need of a large number of their beneficiaries so that we can measure value. So CMS, you can only address this, CMS, if you're listening.

And the last is a gap just to add to your list. Stage 4, one of the measures talked about stage 4. We don't restage. NIH, National Library of Medicine, any source you'll go to, we don't restage. In other words, you can't look in data, and looking at natural language is the least feasible way of doing this. And so that wasn't part of our discussion because that's not our charge, but it really is a gap. And the bigger issue is that we should always be looking at pain. We don't have to wait until somebody is stage 4.

So in terms of addressing these kinds of measures, that's a fundamental flaw. It will not be easy for anybody to look at or address from a systems perspective, maybe from an individual provider perspective. But we really have to systematize to optimize the use and usability, so I just share that.

MS. JOHNSON: Thank you. And then I'll go over to Tracy.

MEMBER SCHROEPFER: So I just wanted to put out there I think that I agree with Laura about the issue of palliative care and the confusion around that and that what I think would be an interesting measure would be one that really asked patients were they offered palliative care. My brother has stage 4 lung cancer, and his oncologist, I told him to ask him about palliative care, and the oncologist, he said, "No, we don't do palliative care. You're not hospice yet," and so I told my brother to go back and here's the definition, and he did. And so now he's getting palliative care.

And then the other thing is the insurance piece of that and insurance companies. Just because the other thing, he's been waiting three weeks for approval for chemo for palliation. So I think there is a lot of issues around that.

MS. JOHNSON: Thank you. Linda?

MEMBER SCHWIMMER: I had a comment on the reference to ethical and legal in the document, and I think this relates to what we were talking about yesterday where we were talking about the post forums and advanced care directive and lack of clarity or enough information or legally-binding information, and so we're measuring all these things, and we have this different terminology in some of these measures, but will it actually even make a difference? And we're here to make a difference.

And so I think that there's a way for us to do that in terms of working with the legal community, with surrogates, and to maybe -- looking at documents, whether that's documents that become part of this process or whether -- I'm not exactly sure, but I do think that's something that we should look at. I know it's state by state, and I know that there are some models, though, that are accepted across state lines. And to think about that, to then ensure that all this work, in terms of asking if they have an advanced directive or making sure that it's in the chart or in the electronic records, et cetera, it all kind of falls apart when you get to the legal aspect of it, which seems like such a waste, right?

So, you know, I'd love to be able to figure out how to do that as the only lawyer on the Committee. So thank you.

MS. JOHNSON: All right. Last word, Arif.

MEMBER KAMAL: So I'd like to put my full enthusiasm and energy behind the idea of a white paper manuscript, something that sort of carries forward for the field because all of us, I think, individually could write a letter to the editor, and some of us have, in fact, done that kind of thing. But that single voice only carries so much. I think the voice of this group would be really important.

I additionally reflect on the fact -- so my brother is an orthopedic surgeon, and so the quality of his care is evaluated by how he cuts, okay? And when I wear my oncologist hat, the procedure that I perform would be to provide chemotherapy in a very superficial, I'm wearing my, you know, oncologist hat only, way. And so most of the quality measures that are in oncology have to do with timeliness and appropriateness of the chemotherapy that I perform.

In the field that we're in, when my brother asked me so what is it that you actually do, I say we communicate with people. And so he, being a quality person, said, so where are all the quality measures about evaluating how often and how well you communicate with people? And I looked and said uh --- right? And he said, "Well, you would evaluate us on how we cut, right?" And so we should be evaluated on how we have family meetings, do prognostic disclosures, share information. All these things are very unstandardized, right? How many of us in the room have received formalized feedback on conducting a family meeting, right? Especially if you didn't do a fellowship where maybe it was required but, otherwise, sort of how often do we receive that feedback? How often do we receive that feedback from patients outside of HCAHPS scores where we might get that as individuals, et cetera. So I think we should re-evaluate what we do as our procedure and then how are we evaluating from a quality measure perspective.

MS. JOHNSON: Very interesting. And, actually, I'm really looking at time here. Let's go to the next slide about our off-cycle because a couple of you I think talked about this a little bit and have given some ideas already, the white paper idea for example, maybe even Linda's ethical legal looks.

We will be doing off-cycle activities. What does that mean? That means we're going to finish up this endorsement process. We've got another four or five months, six months, something like that, Rachel would know better, to finish this process up. But then after that, we're going to gather you guys together quarterly after that to do some other work, and this is just some ideas on what some of this other work might be. It could be pulling you guys together to help other committees think about something. If something comes along, it's in your wheelhouse, but maybe another group is looking at it. You guys could help.

And I'm going to read this whole thing. Ad hoc reviews if something comes in that we need another endorsement look. Educational activities either to our membership or to other committees, et cetera. So there's lots of things that we could potentially do.

I don't -- we don't have time, actually, unfortunately, to start our brains going on that. What we do have, and I just want to get your feeling on this, and whichever way it goes is fine. We have a meeting scheduled by phone in about a week or so. It should be on your calendars. Thank you. I'm stealing Rachel's thunder a little bit here. That call was set up really to get some time on your calendars. You guys are busy. We wanted to get that time on your calendar for the idea that if we didn't finish our work today, we would have that call, and we could finish up a measure evaluation if we needed to.

Do you have any appetite for continuing this discussion and potential ideas for off-cycle work on a call next week? That's one option. It's already on your calendar. Or would you rather wait, we'll do some back and forth and maybe some polling through email or other ways, when we get a little bit closer to our first-quarter off-cycle work?

So do you care one way or the other? I don't want to use your time if you don't think it's worth it on this call next week.

MEMBER HANDZO: I vote for an email poll.

MS. JOHNSON: Okay. So we got two

emails. Is that okay with everybody? Okay. We'll do that on email. I can't think of any reason that we would need to have that call. It's the post-meeting call, May 20th. Am I missing something? Is anybody -- no, we don't have to vote on that. All right. Yes? That's the August 3rd. All the consensus not reached stuff that happened -- so apologies. This post-meeting call is kind of new, and, again, we put it on your calendars just in case we don't finish something today. If we had 30 measures, and we just couldn't get through all of them, we would have this call.

We will -- again, sorry, Rachel, stealing your thunder here a little bit. We will write up our report, and we put that out for a 30-day public and member comment period. When those comments come through, we as staff will take those comments and gather them together. We will provide draft responses from you guys, and then we'll get you on the phone, and we're going to talk about those comments. And some of those comments may very well make you want to reconsider some of the decisions that were made today, and, if that's so, that's fine because that's part of what the comment period is for. And at that point, the consensus not reached measures will also be readdressed. So, again, that's in August. Found time, yes. You guys just found two hours, yes.

Now, I know we still have to do public comment and next steps. I want to take about four minutes, according to that clock, and get a little bit of feedback from you guys on our process. And I'm particularly interested, if you think it's great, we love that kind of interesting feedback, but maybe what do we need to do better? And specifically we have this new maintenance process that you guys are seeing. You're some of the first ones to have seen this. How is that working for you? The preliminary analysis that we as staff did, how did that work? The ratings that we did as part of the preliminary analysis, was that useful or not?

Anything else is on the table, as well. I realize I've given you three minutes, but if there's anything that you really think we need to work on, we'd like to hear. And Amy?

MEMBER BERMAN: I thought the process was exceptional. The staff was exceptional, as well. In the PDFing of the document, it wasn't in numerical order throughout, so that made it a little harder when we wanted to go and turn to -- it should either be in the order of the agenda or in numerical order so that it's easy for us to find in the PDFed version.

MS. JOHNSON: Okay. And we'll get with you. I'm not exactly sure which PDF, so I'll talk to you offline to make sure I understand that one. Okay. George?

MEMBER HANDZO: Two things. I think the orientation for me was extremely helpful. I would have, in addition, in retrospect, benefitted from more of an opportunity to run through a case example and actually discuss it, you know, not just read here's a good one but what we were looking at what did we get; what are the questions, and that would have just made my life much easier.

I had -- I don't know if anybody else, but the hyperlinks from the staff document to the regular document, I got there, but then I had to scroll back.

MS. JOHNSON: Oh, you couldn't get back?

MEMBER HANDZO: I couldn't get back.

MS. JOHNSON: You're a Mac user?

MEMBER HANDZO: Yes.

MS. JOHNSON: Yes, there's a special command for Mac users. So we are going to add that but --

MEMBER HANDZO: Guess what? Mac is taking over the world. Get used to it. Mac users need some love here.

MS. JOHNSON: Okay, great. Thank you. Deborah?

CHAIR WALDROP: I just can't say enough in terms of thanks to the staff for the measure evaluation worksheets. They were really terrific. Thank you for that and for all of your responsiveness and help with questions.

MS. JOHNSON: Amy?

MEMBER SANDERS: I thought the algorithms were particularly helpful, especially as sort of a first-time NQF participant. And the one thing that would have been helpful for me, but this may not be universal, because of the nature of my work, it was a touch-and-go kind of thing about whether or not I was going to be able to have the time to commit, not in general but because I'm planned out fairly far in advance. And this was all really sort of set up less than two months from the time of the actual meetings, and, for me, more lead time would have been helpful. But that probably, for the overall NQF process, I can see where that would be also problematic, and maybe dealing with squeaky wheels like me is easier on an ad hoc basis than reconfiguring the entire world.

MS. JOHNSON: Thank you. Appreciate

it. Laura?

MEMBER PORTER: I think it would have been helpful to get all of the comments from the workgroup call. Don't tell me we had them posted. Oh, good, okay. I've missed enough things today.

MS. JOHNSON: A workgroup summary, is that what you mean?

MEMBER PORTER: So a workgroup summary. Yes, I think that would be helpful.

MS. JOHNSON: We actually did, just so you know, we did used to do that. When we instituted those preliminary analysis, those take our staff so long that we ended up having to push our time line, but we can only push so much. So one of the things that we said is we will take out those workgroup summaries.

So, you know, nothing is ever written in stone here. They could come back. But we appreciate the feedback. Tracy?

MEMBER SCHROEPFER: So I did the 2012 when we did that, and I just want to say I thought this was great. I thought everything -- you all made so many improvements and changes. And in particular, the only thing I can say for the two is that it always seems like we're so short of time by doing it just for a day and usually it's not quite a half. Sometimes I think maybe linking it to two full days and then the half might be helpful because I think sometimes people do want to say more, and they feel rushed. So that's one thing, and it would have been neat to be able to do some of this today.

And then the other thing is the dinner. I thought the dinner was really great because it gave us a chance to get to know each other a little bit, particularly since we'll be a standing committee, and maybe just getting that information ahead of time because some people couldn't come because they had already made plans. But that was great.

MS. JOHNSON: Okay. Great, thank you. And, Doug, last word on this?

MEMBER NEE: Sure. I'd like to echo

what Tracy just said. Having been at the previous one, this is light years better than it was before, for perspective for those of you who weren't. Yes, everything went wonderfully well.

I think the workgroup sessions were helpful. There was a certain dynamic difference between the workgroup session on the phone and what we actually do here. If it's at all possible, and I emphasize that, if you had recordings of a session where we went from A to Z through a process and a measure, we went through a measure, that someone who hadn't been on this committee before could actually listen to, not the shortcutting we got into, you know, later on in the afternoon and today but, I mean, just a full-on, you know, here's how we went through everything, what the call was, what the responses were, and how the information was provided by those that were leading the discussion I think would be extremely helpful to those who haven't ever been on this before. And it may very well help them put all of the written material that they have in front of them that they're trying to desperately digest into some sort of verbiage that makes sense and is not embarrassing when they get to the meeting here.

MS. JOHNSON: Great suggestion. Thank you. That's actually a pretty easily doable one. And, Amy, something burning?

MEMBER SANDERS: Burning a little bit, yes. Thank you. So one way that you might be able to eat your cake and have it, too, with regard to a post-working group pre-meeting summary would be to task the primary respondent for a given measure with writing up a summary, which I think would provide a summary for other people and would also help the primary discussant to be prepared in a smooth fashion. So speaking only for my own presentation yesterday, that could have gone a little bit more smoothly I thought, and perhaps if I had that kind of extra step, I would have made a better presentation. So just a --

MS. JOHNSON: Very interesting. As

staff, I'm like, oh, wow, give it to somebody else. That's an interesting idea. Thank you so much. With that, let's go to public comment, Rachel, and then tell us our last steps.

MS. ROILAND: Operator, if you could open the lines for public comment, that would be great. Thank you.

OPERATOR: Okay. At this time, if you would like to make a comment, please press star and then the number 1. There are no public comments at this time.

MS. ROILAND: All right. Are there any public comments in the room? All right. So there are no public comments. And I'm actually going to turn it over to Jean-Luc to close us out.

MR. TILLY: That's right. So we talked a little bit about the post-meeting call, which we won't be having, so strike that. We'll post the draft report for public member comment a little bit later in June and give you a couple of months to think about that and write about it.

We'll reconvene on August 3rd to write up our comments and our responses.

Again, the report will be posted for a little bit of a shorter period, just two weeks, for NQF members to vote and the CSAC, or the Consensus Standards Advisory Committee, will get a chance to look at it and approve it, as well as our board and take the next step with that.

Then we'll have a little month period for appeals, and unless there are any or depending on how those are adjudicated, we'll close out at around November or early December. That's pretty much all there is unless you have any questions.

MEMBER RITCHIE: Do you have any idea about what the schedule is for next year?

MS. JOHNSON: No, we haven't, but we would probably be smart to try to think on your calendar sooner, rather than later. That's actually a really good idea, so let me see what we can do with that and try to do that.

MEMBER TATUM: So for my clinic, they

like six months' notice to --

MS. JOHNSON: Six months. Okay. We might could do six months. We might could do six months if we start now, yes.

This has been lovely. Thank you so much. I know this is hard work. I know there's a lot of nuances. I know you're volunteers and you actually have another life outside of our world, but we appreciate it very much. I've really enjoyed getting to talk to you guys and know you guys a little bit better.

So thank you. Safe travels.

(Whereupon, the above-entitled matter went off the record at 2:01 p.m.)

CERTIFICATE

This is to certify that the foregoing transcript

In the matter of: Palliative and End-of-life Care
Steering Committee Meeting

Before: National Quality Forum

Date: 05-11-16

Place: Washington, DC

was duly recorded and accurately transcribed under my direction; further, that said transcript is a true and accurate record of the proceedings.

Neal R Gross

Court Reporter