

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

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Services Research and Quality, Healthcare
Chaplaincy

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Quality and Outcomes Officer, Duke Cancer
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ALICE LIND, Manager, Grants and Program
Development, Health Care Authority*

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ALVIN MOSS, MD, FACP, FAAHPM, Director, Center
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Center of West Virginia University

DOUGLAS NEE, Pharm D., MS, Clinical Pharmacist

LAURA PORTER, MD, Medical Advisor and Senior
Patient Advocate, Colon Cancer Alliance

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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 &
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DEBRA WIEGAND, PhD, MBE, RN, CHPN, CCRN, FAHA,
FPCN, FAAN, Associate Professor with
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of Nursing

NQF STAFF:

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

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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

1 yesterday afternoon. And I'm sort of thinking of
2 that as the transitions in care measures. And
3 I'm going to facilitate that discussion because
4 Sean is on a number of those measures as a
5 discussant. And then Sean will facilitate the
6 CAHPS discussion. Oh, closer, sorry. And then
7 Sean will facilitate the CAHPS discussion because
8 I was on that as a discussant.

9 So I think we'd like to begin with
10 0211, which is proportion of patients who died
11 from cancer with more than one emergency
12 department visit in the last 30 days of life.
13 And I would like to invite our ASCO colleagues to
14 come and talk with us about the measure.

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

18 DR. EVANS: Okay. Thanks. So, just
19 to introduce myself, my name is Tracey Evans.
20 I'm a thoracic medical oncologist at the
21 University of Pennsylvania. I'm here
22 representing the ASCO measure developers for

1 these measures. I am a member of the Measures
2 Task Force. I'm a volunteer for ASCO.

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

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

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

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

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

22 So I also have members -- none of us

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

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

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

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

22 MEMBER RITCHIE: Great. So we're

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

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

16 And, in fact, when you look at the
17 evidence that was provided by the developers,
18 most of the evidence is by extrapolation. That
19 is, that the question of how ED visits in the
20 last 30 days of life influenced patient outcomes
21 is one that one has to sort of make a few
22 assumptions about, and it is not altogether clear

1 that it is associated with better or worse
2 outcomes. Unlike, actually, ICU data, which is
3 much more clear about the relationship between
4 ICU care in the last 30 days of life and patient
5 and caregiver outcomes.

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

17 And then there's, I think, as
18 mentioned -- well, there was an ASCO sort of
19 provisional clinical opinion in 2012, and then a
20 Cochrane collaborative systematic review that
21 looked at, again, models of care for patients
22 with cancer and found that those who received, in

1 this instance, home-based palliative care, had a
2 decreased risk for dying in the hospital, but it
3 didn't actually reduce number of ED visits.

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

18 And so I'll stop there.

19 CHAIR WALDROP: Anything to add, Paul
20 or Sean?

21 (No response.)

22 CHAIR WALDROP: Okay. Let me open it

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

4 MEMBER ARCHULETA: Yes, this is Bob.

5 CHAIR WALDROP: Hi, welcome.

6 MEMBER LIND: Yes, this is Alice.

7 CHAIR WALDROP: Great, welcome.

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

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

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

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

19 But, at the same time, calls into
20 question if we're giving -- if we're giving toxic
21 therapies to people, we should have the
22 infrastructure to take care of them, especially

1 during business hours.

2 CHAIR WALDROP: Thanks. Other
3 comments?

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

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

18 MEMBER KAMAL: I might also put out,
19 so Toby Campbell and Jim Cleary did a really nice
20 study a couple of years ago looking at the
21 University of Wisconsin experience, and really
22 showed that the patients admitted to their

1 oncology wards, by far the admission, you know,
2 to being seen in the hospital in an unanticipated
3 way was a predictor of death within six months.
4 So I think that's a very cogent to this room,
5 which is that that we also see as an avoidable
6 piece of information.

7 The other thing from Deb Mayer's study
8 shows that, of those seen in the ED, those like
9 1.7 million visits in her study in JCO, only
10 eight percent of those patients were admitted,
11 which means 92 percent were seen for something
12 that did not require a hospitalization. So, if
13 it's febrile neutropenia, it was low risk. If it
14 was pain, that means they just needed a
15 prescription, right. If it was anemia, they got
16 a transfusion and left.

17 So it calls into question, can those
18 92 percent of people who don't actually need a
19 hospital bed be treated in a different way,
20 especially if half of them came between 8:00 and
21 5:00 when the oncologist is sitting in the
22 office.

1 CHAIR WALDROP: Thank you.

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

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

17 MEMBER NEE: Just, Christine, I mean
18 I hear the rural argument, but is not the flip
19 side of that that, if we have this measure and
20 people are being seen in EDs because that's the
21 only place -- I mean, we're not going to stop
22 people from going to EDs because we pass this

1 quality measure. They're going to still show up
2 in their ED. But isn't the counter-argument to
3 that that that then points up and -- you know, as
4 Arif I think is signaling -- raises the issue of
5 we need an alternative because look at all of
6 these people who are showing up during business
7 hours in our EDs.

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

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

20 MEMBER TATUM: I was just going to
21 make the point, I think we went almost an hour on
22 this particular metric, and I'm not sure that's

1 going to move us forward on where the evidence
2 ranks right now.

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

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

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

22 So, you know, I hesitate to bring that

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

5 CHAIR WALDROP: Would you care to
6 comment on that?

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

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

1 call it an exception?

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

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

12 (No response.)

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

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

20 MEMBER BERMAN: Reminder, I'm a
21 recusal.

22 CHAIR WALDROP: Thank you for

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

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

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

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

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

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

22 CHAIR WALDROP: Great, thank you. So

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

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

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

13 (No response.)

14 CHAIR WALDROP: Any comments from the
15 committee?

16 (No response.)

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

19 (No response.)

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

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

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

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

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

22 And I think this is where the work

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

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

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

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

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

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

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

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

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

21 I think really the main question was
22 what was going on with the claims data in terms

1 of the death registry. So I think the
2 insufficient was related to not having clarity
3 about that in the specifications, as well as not
4 having any testing for that piece of the measure.

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

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

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

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

22 CHAIR WALDROP: Oh, I'm sorry. Go

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

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

9 MS. BOSSLEY: So I think, in this
10 measure specifically, no, because it has not been
11 implemented in QOPI. If you look at the other
12 measures, there are five in total. Three are
13 used in QOPI. That might give you -- that
14 information from that might give you a sense of
15 how this measure might perform but,
16 unfortunately, that would be all we could provide
17 at the moment. I don't know if that helps, but -
18 -

19 CHAIR WALDROP: Michelle?

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

1 MEMBER RITCHIE: Go ahead, Sean.

2 CHAIR MORRISON: It doesn't matter.

3 We came down on insufficient pending whether --
4 asked the developers could come back and clarify
5 where they were going to get the denominator
6 files from. I think we all felt that if they
7 were coming back with registries we would
8 probably be fine with it.

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

15 CHAIR WALDROP: Paul?

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

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

1 MEMBER TATUM: Right.

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

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

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

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

20 CHAIR MORRISON: Welcome to scientific
21 peer review process.

22 MEMBER RITCHIE: Okay.

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

4 CHAIR WALDROP: Arif?

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

16 So, you know, this is unique data but
17 the ability to arrive at these conclusions, I
18 think, is similar, just probably delayed in a
19 normal abstraction period of time, because we
20 have to do this. Every cancer center has to
21 report this data, has to know the mortality. We
22 just end up knowing it six months down the road,

1 not in time for, you know, this kind of
2 publication.

3 CHAIR WALDROP: Two more. Christine?

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

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

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

16 MR. TILLY: To vote on reliability for
17 0211, select 1 for high, 2 for moderate, 3 for
18 low, and 4 for insufficient.

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

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

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

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

17 And then, with respect to face
18 validity, the developer stated that face validity
19 was assessed. There was some focus groups
20 conducted and then vetted by an expert panel of
21 cancer patients. The challenge was we just
22 didn't have a lot of information, and our

1 understanding from what NQF requires is that they
2 require a little bit more detail around face
3 validity testing.

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

9 CHAIR WALDROP: Paul and Sean,
10 anything to add?

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

14 MEMBER MORRISON: I think I was one of
15 the strongest proponents that this measure -- the
16 time had come for risk adjustment, that there --
17 when you think about the unintended consequences
18 of vulnerable patients who need to be protected,
19 who (a) live in settings where hospice is not yet
20 available, (b) in the inner cities, and (c)
21 because this is a measure that applies to group
22 practices and clinicians and not to GRG-exempt

1 cancer hospitals, the easy way to avoid this
2 measure is to tell your patient at home, don't go
3 to the ED.

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

13 CHAIR WALDROP: Other questions or
14 comments?

15 (No response.)

16 CHAIR WALDROP: Are we ready to vote
17 on validity?

18 (No response.)

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

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

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

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

15 CHAIR WALDROP: Christine?

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

20 CHAIR WALDROP: Paul?

21 MEMBER TATUM: I actually think there
22 was a comment where there was some consensus

1 that, if we had risk adjustment, we agreed we'd
2 move the subcommittee tomorrow.

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

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

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

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

17 If we go that route, again, not
18 something that we would do often, we would
19 have -- and I'm pulling up our policy right now.
20 Basically, the idea is, if it's a risk adjustment
21 question and if the developer is thinking that
22 risk adjustment is the way that you would be

1 proceeding, which is not completely for sure,
2 right. We don't know that yet.

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

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

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

15 So risk adjustment is not something
16 we've done with the QOPI metrics because they've
17 been practice-specific and meant to compare
18 practices to themselves and give them an
19 opportunity to improve. None of these are meant
20 to be zero numbers. We weren't meant to have
21 people never come to the ED. But, certainly, I
22 think, for patients with advanced cancer who are

1 within 30 days of death, multiple ED visits is a
2 bad thing and not the optimal way to take care of
3 these patients. And capturing that is important.

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

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

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

22 CHAIR WALDROP: Sean?

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

11 CHAIR WALDROP: Arif?

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

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

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

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

19 The other thing that might be helpful
20 for ASCO to hear from this group is on what
21 specific -- other than demographics -- should we
22 be risk-adjusting on, because it sounds like, in

1 addition to the patient population, we should
2 think about the environment, the neighborhood,
3 and potentially even the characteristics of the
4 cancer center itself, right.

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

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

22 Sorry, my friend.

1 CHAIR WALDROP: Cleanne and then Paul.

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

15 CHAIR WALDROP: Paul?

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

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

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

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

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

17 Where we will be formal is we have to
18 come to some kind of timeline that we agree to.
19 And I'll read our policy. The steward developer
20 must confirm the feasibility of the changes,
21 agree to the timeline, and follow up with our
22 staff. So we will be doing this. Within 14

1 days, we'll be asking for a plan of how that
2 would go forward.

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

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

22 Because all of those questions haven't

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

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

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

13 MS. JOHNSON: Okay.

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

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

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

21 So we will move on to measure 0213,
22 proportion of patients who died from cancer

1 admitted to the ICU in the last 30 days of life.
2 And I'll ask our developer colleagues if you have
3 anything further you want to add about this
4 measure.

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

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

12 So we're looking at measure 0213.
13 This is the proportion of patients who died from
14 cancer who were admitted to the ICU in the last
15 30 days of life. And I cut in. Did you guys
16 have any other comments you wanted to add on
17 that?

18 DR. EVANS: We're okay.

19 MEMBER TATUM: So this looks at
20 proportion of patients who died from cancer
21 admitted into the ICU in the last 30 days. We
22 have at the evidence level -- and, again, our

1 numerator being dying from cancer and in the ICU
2 in the last 30 days, and the denominator being
3 deaths from cancer.

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

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

19 They have similar -- prior review had
20 a retrospective covert study. There's consensus
21 statement data. The update included a Cochrane
22 systematic review, which looked at cancer patient

1 in home-based palliative care services and found
2 increased chance of dying at home and reduced
3 symptom burden. A little bit indirect, not ICU
4 metrics. But, if you're dying at home, you're
5 not necessarily in the ICU.

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

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

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

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

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

5 (No response.)

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

9 Okay. No questions or comments on the
10 evidence?

11 (No response.)

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

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

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

21 CHAIR WALDROP: Okay. Thank you. So
22 we'll move on to consider gaps in care,

1 opportunities for improvement, and any issues
2 with disparities.

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

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

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

20 (No response.)

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

1 (No response.)

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

6 MEMBER LIND: Nothing, thank you.

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

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

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

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

21 MEMBER TATUM: This is somewhat
22 similar to where we were on the previous

1 discussion. This data comes from administration
2 claims as well as registry. Our big topic of
3 discussion was how we get to the death data piece
4 on the registry.

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

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

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

1 CHAIR WALDROP: Any other comments or
2 questions? Woody?

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

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

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

13 (No response.)

14 CHAIR WALDROP: Seeing none --

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

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

22 CHAIR WALDROP: Okay. We'll move on

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

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

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

1 regions.

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

5 CHAIR WALDROP: Any other comments
6 from Sean or Christine?

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

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

20 CHAIR WALDROP: Thank you.

21 MS. JOHNSON: I do have a couple of
22 clarifying -- or, really, just one clarifying

1 question for the developer. Is this a facility-
2 level measure, or is this still a clinician
3 practice measure?

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

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

14 CHAIR WALDROP: Arif and then Gregg.

15 MEMBER KAMAL: Yeah. So I'm just
16 making sure we -- so it's ICU stay, right, within
17 30 days of death? So agnostic as to where they
18 die. But I agree with the point. No, but I
19 agree with the point. The point is the hospital
20 has control over that.

21 I'm actually reassured. And I brought
22 this up on the work group call about the issue

1 of, you know, what is an ICU and so on and so
2 forth. But the really high sensitivity between
3 claims data and medical abstraction data is
4 reassuring to me because you can be on unit 9200,
5 which is oftentimes beds are flexed to an ICU.
6 So an abstractor might say that patient was in
7 the ICU or in an ICU level of care, where the
8 claims says the opposite or either way.

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

16 CHAIR WALDROP: Gregg, did you have --

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

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

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

1 (No response.)

2 CHAIR WALDROP: It looks like it.

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

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

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

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

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

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

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

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

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

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

18 MS. JOHNSON: And I just need --

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

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

3 CHAIR MORRISON: Face validity.

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

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

9 MS. JOHNSON: Okay. Great.

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

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

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

20 MS. JOHNSON: Okay. Okay.

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

1 MS. JOHNSON: Right. And Christine?

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

14 MS. BOSSLEY: Correct.

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

22 Arif, do you want to add to that? I

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

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

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

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

20 MEMBER RITCHIE: Why don't you tell
21 us?

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

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

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

19 CHAIR MORRISON: Yeah. And I think,
20 Karen, to your question, I think, you know, the
21 identification of the denominator through a death
22 registry was critical to us, and not through

1 claims, because we recognized claims was very
2 poor for that. ICU through claims we recognized
3 was very appropriate, and there are a number of
4 studies, for example, Dartmouth Atlas, that have
5 shown that to be both a reliable and valid
6 measure of identifying ICU stay. Not death, ICU
7 stay. Sorry. Stay. Stay. Stay.

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

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

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

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

1 moderate level.

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

4 (No response.)

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

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

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

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

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

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

1 useable.

2 Arif, anything to add?

3 (No response.)

4 CHAIR WALDROP: Sean or Christine,
5 anything to add?

6 (No response.)

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

9 (No response.)

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

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

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

20 CHAIR WALDROP: Okay. And so,
21 finally, we need to vote on the overall measure,
22 whether we vote yes or no, we want to endorse

1 this -- suggest that NQF endorse this measure.

2 MR. TILLY: Polling is now open. Vote
3 1 for yes and 2 for no.

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

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

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

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

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

22 MEMBER VANDEKIEFT: Thank you. So

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

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

14 And so another discrepancy that was
15 noted in the data section or the evidence section
16 was between Medicare and Medicaid hospice
17 referral rates, namely, about 51 percent of
18 Medicaid patients enrolled in hospice, Medicaid
19 patients who died from cancer, compared to about
20 64 percent of Medicare patients.

21 And so, with that evidence together,
22 it was felt that -- the staff that did the

1 evaluation felt that there was a high level of
2 evidence in support of this particular measure.

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

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

18 CHAIR WALDROP: Thanks. Any
19 discussion?

20 (No response.)

21 CHAIR WALDROP: Seeing none, we'll
22 move to voting on the evidence for -- if we're

1 okay with the evidence, we don't need to re-vote.
2 Do we want to vote or just go through it?
3 Okay. Sorry. I'm still stuck on the process of
4 claims.

5 Okay. So --

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

11 MEMBER VANDEKIEFT: That's a sad
12 statement.

13 CHAIR WALDROP: Thank you for that
14 insight, Paul.

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

17 MEMBER VANDEKIEFT: So gaps in the
18 measure so, when you look at the data at the
19 table that's before you, median hospice -- or
20 median number of patients in different studies
21 who died of cancer who were not referred to
22 hospice, is in the ballpark of about 40 percent,

1 which would indicate there is still a very
2 substantial opportunity to improvement.

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

12 CHAIR WALDROP: Thanks. Any comments?
13 Discussion?

14 (No response.)

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

18 MR. TILLY: To vote on a performance
19 gap for 0215, select 1 for high, 2 for moderate,
20 3 for low, and 4 for insufficient.

21 The results are 20 voting high, two
22 voting moderate, zero voting low, zero voting

1 insufficient. The measure passes performance
2 gap.

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

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

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

1 reliability.

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

5 (No response.)

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

10 (No response.)

11 CHAIR WALDROP: Okay.

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

20 So, unlike the other measures this
21 morning where there was a lot of discussion about
22 things like risk adjustment and testing, et

1 cetera, you're not having that on this one. So
2 we don't necessarily need to vote. So is that
3 clear? I don't want people to be unhappy with
4 our process.

5 CHAIR WALDROP: Thanks, Karen, for
6 clarifying.

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

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

21 At that point in time, the staff rated
22 the validity as insufficient to do the poor

1 sensitivity claims data. The numerator came up
2 with about a .24 sensitivity compared to .96
3 specificity, but it was felt that with
4 particularly the registry-based data that there
5 was sufficient information there that that might
6 bump that up to moderate.

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

9 MEMBER VANDEKIEFT: Yeah.

10 CHAIR WALDROP: Okay. Thank you for
11 clarifying.

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

15 CHAIR MORRISON: See my brain this
16 morning.

17 MEMBER VANDEKIEFT: Three hours
18 earlier.

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

1 QOPI nurse extraction the gold standard?

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

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

11 MS. BOSSLEY: Correct. Correct.

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

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

22 (No response.)

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

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

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

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

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

21 (No response.)

22 CHAIR WALDROP: I'm sorry. I have to

1 clarify again. Do we vote to not?

2 MS. JOHNSON: Yes, we vote.

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

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

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

14 Yeah, let's just vote.

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

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

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

22 The results are two voting high, 20

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

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

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

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

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

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

1 case.

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

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

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

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

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

20 MEMBER VANDEKIEFT: Yeah.

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

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

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

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

13 MS. JOHNSON: Right, but I think they
14 were talking about it came from the public
15 comment. So we were just trying to figure out
16 what was said in the public comment that may have
17 --

18 CHAIR WALDROP : So, Michelle, is this
19 the section you're referring to, this -- so these
20 would have been comments submitted through the
21 pre-evaluation survey that committee members
22 submitted. So maybe someone who is not here

1 today submitted that comment, and so that's why
2 we're not having more discussion around it.

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

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

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

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

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

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

1 endorsement.

2 MEMBER VANDEKIEFT: Deborah?

3 CHAIR WALDROP: Yes?

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

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

16 Some of the material that was
17 submitted seemed to conflate the two, and I did
18 not feel that that in any way undermined the
19 validity of this particular measure or the
20 evidence supporting it, but just that callout,
21 keeping hospice and end-of-life palliative care
22 somewhat distinct from early concurrent

1 palliative care is something we need to be
2 cognizant of.

3 CHAIR WALDROP: Thank you for
4 clarifying that.

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

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

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

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

18 The title of this measure is
19 proportion of patients who died from cancer
20 admitted to hospice for less than three days.
21 And I'm going to ask our developer colleagues if
22 there is anything else you would like to add

1 about this measure before we start our
2 deliberations.

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

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

9 MEMBER PORTER: We discussed this
10 yesterday, so --

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

13 MEMBER PORTER: Yes, we have a plan.

14 CHAIR WALDROP: All right.

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

20 The developer did provide updated
21 evidence for the measure, along with a diagram of
22 the relationship, the process of care, and better

1 patient outcomes. They also cited several
2 sources, including three individual articles,
3 2013 Cochrane review, and a 2012 opinion from
4 ASCO that supported this relationship.

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

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

11 (No response.)

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

1 provided at the practice level.

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

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

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

12 MEMBER PORTER: Okay.

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

18 MEMBER PORTER: I am very sorry.

19 MS. ROILAND: That's okay.

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

22 CHAIR MORRISON: I looked at it.

1 There was a gap.

2 MEMBER PORTER: Thank you.

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

5 (No response.)

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

11 So any questions or discussion before
12 we vote?

13 (No response.)

14 CHAIR WALDROP: Okay, Jean-Luc?

15 MR. TILLY: On performance gap for
16 0216, select 1 for high, 2 for moderate, 3 for
17 low, and 4 for insufficient.

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

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

1 reliability testing.

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

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

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

16 MS. BOSSLEY: You mean the question
17 Medicare versus -- so part of this, we're limited
18 with the data set that was available at the time
19 this was tested, which was Medicare data, which
20 is why you see it specific to this. Our hope is,
21 now that it's on the core measure set list, we
22 can start having conversations with commercial

1 health plans, Medicare Advantage plans, others,
2 to answer this and begin to look more broadly.
3 But, unfortunately, we're limited, at least with
4 the claims, to that piece.

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

8 CHAIR WALDROP: Thank you.

9 MEMBER PORTER: Thank you.

10 CHAIR WALDROP: Any other thoughts or
11 comments about reliability?

12 (No response.)

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

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

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

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

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

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

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

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

22 CHAIR WALDROP: Okay.

1 MEMBER PORTER: So where are we,
2 validity?

3 CHAIR WALDROP: Validity, yeah.

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

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

18 CHAIR WALDROP: Okay.

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

21 CHAIR WALDROP: Yes, if you have --

22 MEMBER PORTER: Okay. I'm going by

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

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

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

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

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

22 MS. BOSSLEY: The testing was all done

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

4 CHAIR WALDROP: Okay. Other -- Tracy?

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

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

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

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

18 MEMBER VANDEKIEFT: Yeah. And I was
19 just going to follow up that the developer did,
20 after our work group, call and submit a comment
21 that is available on the SharePoint site
22 addressing that and noting that, in the future,

1 they do have the hope to do the seven-day data.
2 It's just that, right now, there's such a
3 variation in practice across different settings,
4 and three days has been the ones that has been
5 used. And so that is still the standard. But
6 everybody recognizes that longer is better in
7 this setting.

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

10 (No response.)

11 CHAIR WALDROP: Seeing none, I think
12 we are ready to vote on the validity of measure
13 0216.

14 MR. TILLY: Again, this one is a
15 little bit different, since we looked at face
16 validity only. Select 1 for moderate, 2 for low,
17 3 for insufficient.

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

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

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

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

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

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

19 The second was the question about
20 Medicare hospice benefits. So, if you're looking
21 at claims but you don't -- if somebody is not on
22 Medicare, then you can't see if they were in

1 hospice. So I think he answered that.

2 CHAIR WALDROP: Any other questions or
3 comments?

4 (No response.)

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

8 MR. TILLY: To vote on feasibility,
9 select 1 for high, 2 for moderate, 3 for low, and
10 4 for insufficient.

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

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

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

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

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

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

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

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

21 (Simultaneous speaking.)

22 CHAIR WALDROP: Gregg?

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

11 CHAIR WALDROP: Great. Arif?

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

21 But the point being I think they're
22 using that as a balance measure that says, you

1 know, not in our ED, not in our hospital. Get
2 them to hospice. So I think that's how they're
3 balancing it.

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

6 Any other comments? Any other
7 discussion?

8 MEMBER PORTER: I gave it a high
9 rating.

10 CHAIR WALDROP: Okay. Thank you for
11 that.

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

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

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

21 CHAIR WALDROP: So that brings us to
22 the final vote, which is whether or not we

1 recommend this measure as suitable for
2 endorsement by NQF.

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

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

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

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

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

22 CHAIR WALDROP: Okay. Thank you. So

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

4 MEMBER PORTER: Where's Rob?

5 CHAIR WALDROP: He had a family
6 emergency and --

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

10 CHAIR WALDROP: Okay. Okay.

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

13 CHAIR WALDROP: So sure.

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

19 CHAIR MORRISON: Yeah. If we can move
20 through this with staff, I think -- you know,
21 this is very similar to all of the others that we
22 have done, but I think some of the same issues

1 are going to come up or not come up. So I think,
2 if we can push through, let's.

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

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

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

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

1 patients.

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

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

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

1 more complicated immunotherapy.

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

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

8 MEMBER PORTER: Okay.

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

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

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

17 CHAIR WALDROP: Okay.

18 MEMBER PORTER: Thank you.

19 CHAIR WALDROP: Other comments on the
20 evidence, Laura?

21 MEMBER PORTER: Yes. The evidence has
22 been presented in mostly recent literature. The

1 literature is tangential in that none of the
2 articles show the relationship between
3 discontinuation of chemotherapy and desired
4 outcomes, that of negatively impacting the
5 patients' and care givers' experience. So it
6 doesn't directly show that.

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

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

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

18 MS. JOHNSON: We actually tried to
19 note, you know, kind of what we thought the
20 evidence that was presented did, and it did seem
21 a little tangential. It's one of these places
22 where there's not systematic reviews with

1 grading, so you're relying on these articles.

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

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

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

22 CHAIR WALDROP: Thank you. So I have

1 comments from Sean and Karl and Arif.

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

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

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

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

22 CHAIR WALDROP: Thank you. Karl and

1 then Arif, and then Paul.

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

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

18 CHAIR WALDROP: Thank you. Arif?

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

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

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

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

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

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

15 MEMBER ARCHULETA: Yes. This is Bob.
16 Just from an anecdotal perspective and a
17 pediatric perspective, what I'm seeing in the
18 pediatric world is cloaking chemotherapy, is
19 tired of chemotherapy and, therefore, continuing
20 that until the last days of life and happening
21 more and more frequently, certainly in the
22 patient population that I take care of. And I

1 think that that's something that we need to be
2 aware of.

3 CHAIR WALDROP: Thank you. Paul and
4 then Linda?

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

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

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

15 CHAIR MORRISON: Presumably, moderate.

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

21 So, just to make sure that we're all
22 on the same page here, there are a couple of

1 articles that were cited, particularly Greer and
2 Landrum, as well as the one that -- did you share
3 that with the committee, Arif? I don't remember
4 if that was one of the ones, but it seemed
5 familiar when you mentioned it, so I think you
6 probably talked about that on the work group
7 call.

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

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

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

20 MEMBER SCHWIMMER: I just had a
21 clarifying question for the developers and then
22 the committee about the articles. So death from

1 cancer, that's the terminology that's used in the
2 numerator and the denominator. Does that include
3 something like a fall or an infection? I mean,
4 I'm just trying to get a sense of what's included
5 which, I guess, is similar to the earlier
6 comment.

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

14 CHAIR WALDROP: Thank you.

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

20 DR. EVANS: Correct.

21 MEMBER SCHWIMMER: Okay.

22 CHAIR WALDROP: Thank you. Christine?

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

5 CHAIR WALDROP: Okay. So all-
6 inclusive.

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

9 CHAIR WALDROP: Okay. Karl --

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

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

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

19 CHAIR WALDROP: Sure.

20 DR. EVANS: Just to say that you can
21 get dinged for a first course of chemotherapy if
22 a patient dies. I think that's what's makes this

1 actually a good metric, because you don't want
2 that to happen either. And this isn't just a
3 palliative metric where oncologists, you know,
4 want to make sure they're not giving chemotherapy
5 too late in the game. They also don't want to
6 give chemotherapy that's too toxic and make sure
7 that they're doing appropriate supportive care.

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

10 CHAIR WALDROP: Thank you.

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

16 CHAIR WALDROP: Do you want to take
17 that?

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

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

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

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

21 So that, if people believe -- and this
22 is, you know, sort of the difficult part. If you

1 believe that that, as a group, forms enough
2 evidence to move this measure forward, then, you
3 know, that puts it into the moderate or you're
4 very optimistic, the high category. If you
5 believe that -- actually, that the evidence does
6 not exist at all or -- then you need to go into
7 the insufficient. And, if there are enough
8 people who believe that, then we will move to
9 voting for exception or not.

10 Does that help people?

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

13 MEMBER TATUM: I don't know that
14 there's a big -- it's reassuring that there's the
15 opportunity to revisit this should we split
16 50/50, similar to previous parliamentary
17 maneuvers, in case my prior comments sway anybody
18 inappropriately on that first vote.

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

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

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

20 Does that make sense? Arif?

21 MEMBER KAMAL: Yeah. And I'm not
22 going to try to confuse the picture. It's

1 helpful that ASCO has provided sort of a
2 standardized definition of what's antineoplastic
3 therapy. Note that that's the term they use,
4 which I think is the term we used in palliative
5 care to a cancer-directed treatment, which is
6 truly all-encompassing minus hormonal therapy,
7 which is just a good caveat to add.

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

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

21 I think ASCO, in a standardized way,
22 and I think in the oncology profession in a

1 standardized way, we are looking at novel agents
2 not any differently in terms of their efficacy in
3 the last two weeks of life.

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

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

21 CHAIR MORRISON: And I think the other
22 comment I would make that might be helpful before

1 we vote is that, if this committee was the
2 endocrine committee or the orthopedic committee
3 or, indeed, the oncology committee, and we were
4 looking at a quality measure that looked at a new
5 therapy or drug, we would be saying, does this
6 have benefit rather than does this have side
7 effects.

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

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

22 CHAIR WALDROP: Yes. Thank you very

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

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

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

14 (No response.)

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

17 MR. TILLY: Yeah, that's right. To
18 vote on the evidence for 0210, select 1 for high,
19 2 for moderate, 3 for low, and 4 for
20 insufficient.

21 Okay. The votes are one voting high,
22 19 moderate, one low, one insufficient. The

1 measure passes evidence.

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

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

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

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

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

1 (No response.)

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

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

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

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

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

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

21 (No response.)

22 CHAIR WALDROP: We could suspend a

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

4 (No response.)

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

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

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

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

20 MEMBER PORTER: Yes.

21 CHAIR WALDROP: Okay.

22 DR. EVANS: Well, I'm getting

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

5 MEMBER PORTER: Yes. Yes.

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

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

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

22 CHAIR WALDROP: Thank you so much for

1 clarifying. I appreciate that.

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

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

17 I don't think that's an argument for
18 risk adjustment right now. I think it's just
19 something to note, that there are other sort
20 of -- all cancers are not all cancers, right,
21 that there are populations that -- in the future,
22 I think we would hope that there may be a

1 potential new measure that addresses heat
2 malignancies or bone marrow transplant or
3 something else.

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

6 Anything else? Christine?

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

14 CHAIR WALDROP: Do you want to
15 comment?

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

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

1 find, yeah.

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

5 (No response.)

6 CHAIR WALDROP: Okay. Seeing none, I
7 think we are ready to vote on the validity of
8 0210.

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

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

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

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

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

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

8 (No response.)

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

12 (No response.)

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

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

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

21 MS. JOHNSON: I think I'm going to ask
22 you to actually do the vote on this one because

1 the last time you actually did vote because there
2 were questions about usability and use in the
3 programs, et cetera. And I'm not quite sure
4 which vote we'd be carrying over at that point,
5 so --

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

9 (No response.)

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

12 MR. TILLY: To vote for usability and
13 use for 0210, select 1 for high, 2 for moderate,
14 3 for low, and 4 for insufficient information.

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

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

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

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

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

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

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

17 And Karl has a comment before we
18 close.

19 MEMBER STEINBERG: I was just hoping
20 that maybe right before we reconvene to continue
21 working, maybe we could get a picture that I
22 could post on Twitter of those who don't mind

1 being in like a group picture.

2 CHAIR WALDROP: Thank you. We'll take
3 a break and we'll resume at five minutes of
4 11:00? We'll resume at five minutes of 11:00.
5 Thank you.

6 (Whereupon, the above-entitled matter
7 went off the record at 10:41 a.m. and resumed at
8 11:00 a.m.)

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

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

22 So, we have CMS here, I gather.

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

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

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

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

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

1 included.

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

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

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

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

21 The Hospice CAHPS questionnaire has a
22 total of 47 questions. All respondents do not

1 always answer all questions, but they generally
2 do answer most of them and -- or we ask them to.
3 The measures we have submitted to you today are
4 all based on survey items.

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

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

15 And for a short bit of background:

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

1 AHPS? -- the CAHPS survey family.

2 Thank you.

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

5 (No response.)

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

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

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

22 So, for example, if we are voting on

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

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

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

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

19 MEMBER TATUM: That's from pre-photo.

20 CHAIR MORRISON: Pre-photo, okay.

21 So we're going to start, we're going
22 to start with evidence. I am just going to read

1 the domain items and ask if anybody would like
2 one of them pulled. They are communication;
3 timely care; respect, emotional and religious
4 support; symptom; training; rating of care; and
5 willingness to recommend the hospice team.

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

8 (No response.)

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

11 Deborah, it's all yours.

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

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

22 The exclusions to this are also

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

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

18 And they, they focus on evidence in
19 terms of interdisciplinary assessment, care plan
20 documentation, timeliness of visits, the
21 sensitivity of communication, how staff treats
22 patients with dignity, how the patient is

1 screened for needs and an in-depth assessment, an
2 individualized care plan, and how the plan is
3 monitored for goals, and also the relationship
4 that's fostered with the patient's clergy and
5 hospice staff provided training. So all these
6 elements were looked at in terms of evidence.

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

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

16 CHAIR MORRISON: Questions from the
17 committee or others?

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

20 Amy, go ahead.

21 MEMBER BERMAN: So just one additional
22 comment. It's not listed under the exclusions,

1 but the way in which this survey is done, we do
2 not do this survey to those places that serve
3 less than 50 people per year. And so just in
4 understanding in terms of the evidence, you know,
5 then for rural and frontier, you would likely not
6 have evidence complete.

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

11 CHAIR MORRISON: Great. Thanks.

12 Thanks, Amy.

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

22 MS. DEAN-WHITTAKER: We decided to

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

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

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

20 In terms of public reporting, 12 is
21 such a small number that it's not reliable. It
22 will jump up and down and, therefore, could give

1 a very unfair rating to a hospice. So we don't,
2 we will not publicly report the real small ones
3 either.

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

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

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

20 But, as Deborah mentioned, it would be
21 basically impossible to publicly report it for a
22 couple of reasons. One is that fewer than a

1 certain number of responses we would be concerned
2 about identifying a respondent, but also it would
3 be too small a number to reliably reflect on the
4 quality of care provided by the hospice.

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

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

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

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

21 So that exclusion refers to people who
22 don't speak any of the above language that I just

1 mentioned. And, again, we've, CMS has solicited
2 input over the last couple of years, and
3 continues to, about what additional languages
4 would be useful to hospices to make sure that
5 that exclusion from the denominator is minimized.

6 MEMBER SCHROEPFER: Great. Thank you.

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

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

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

22 So do I have other questions,

1 discussion about the evidence for this measure?

2 MEMBER LIND: Hi. This is Alice. Can

3 I ask a question?

4 CHAIR MORRISON: Yes. Alice, go right
5 ahead.

6 MEMBER LIND: Hi.

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

9 Go ahead, Alice.

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

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

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

22 So the requirements in terms of

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

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

14 MEMBER LIND: Thank you.

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

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

21 MR. TILLY: So to vote on evidence for
22 2651, select 1 for yes, and 2 for no.

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

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

14 (No response.)

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

17 CHAIR WALDROP: Okay. So a couple
18 things I want to remind you of first. That this,
19 the multi-item measure scores were calculated as
20 the average proportion that gave responses in the
21 most positive categories. And the measure was
22 adjusted for the mode of administration. So you

1 heard Debra tell us that it was by mail only, by
2 telephone or by both. And so it was adjusted in
3 that way.

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

10 I think in our work group conversation
11 we had talked about what do I do with a mean of
12 85? But it indicates that there's still
13 opportunity for growth and for improvement,
14 especially when we think about communication, we
15 think about all of these elements. It's always
16 important to get them as high as we can.

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

1 domains.

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

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

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

12 MEMBER PURSLEY: Non-work group.

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

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

20 So consequently, when you ask a
21 question such as Did you feel the hospice team
22 really cared about your loved one? and you're

1 expecting a "percent always," I think that you're
2 trying, unless you take "usually" and "always"
3 together as top box, there are many people who
4 just aren't going to say "always."

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

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

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

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

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

22 MEMBER PURSLEY: Okay.

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

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

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

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

21 MEMBER PURSLEY: Yes.

22 CHAIR MORRISON: Okay, great. Thanks.

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

7 George.

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

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

19 So again we're voting on all eight
20 domains in aggregate. So there will be one vote.
21 And this is on the performance gap on
22 disparities. And, again, we've got high,

1 moderate, low and insufficient.

2 Right, Jean-Luc?

3 MR. TILLY: That is exactly right, yes.

4 CHAIR MORRISON: Excellent. Getting
5 the hang of this.

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

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

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

18 (No response.)

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

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

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

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

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

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

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

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

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

22 CHAIR MORRISON: Christine.

1 MEMBER RITCHIE: So, in some of our
2 previous measures we basically said that the
3 threshold for reliability was point 7. And, you
4 know, granted some of these are close, but point
5 6 I would argue is not close. I just wanted to
6 sort of get clarity about whether or not we're
7 changing our consensus about what the threshold
8 is.

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

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

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

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

15 CHAIR MORRISON: Amy.

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

22 CHAIR MORRISON: I'm sorry, those are

1 a, that's a, it's a -- I'm sorry, Deborah, you
2 can answer. I was going to. It's a yes/no.
3 It's not a -- it's a single item. It's a single
4 item so the Cronbach's alpha doesn't apply.

5 Cindi and then Tracy.

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

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

11 Tracy. Please. That's okay.

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

20 In some ways they're different and
21 someone may not want religious support but want
22 emotional support. Or I just am just wondering

1 about that. And I think the reliability speaks
2 to my concern.

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

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

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

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

1 CHAIR MORRISON: Yes, Michelle. And
2 then George.

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

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

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

19 MEMBER HANDZO: Yeah, on the
20 spirituality and --- this has been a bone of
21 contention. Press Ganey has done the same thing
22 historically, as many know. And I don't know the

1 right answer. I'm appreciative of the data which
2 suggests that it actually enhances the Cronbach's
3 alpha which is probably the first data I've ever
4 seen that actually gets to this question.

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

10 CHAIR MORRISON: Other comments?

11 (No response.)

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

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

19 So we are being asked to look at two
20 things. One is, within each of the items, okay -
21 - or, sorry, within each of the domains do the
22 items hang together reasonably well so that they

1 are essentially measuring one concept? And that
2 is the Cronbach's alpha measure.

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

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

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

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

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

21 Does that help? Okay.

22 Sorry. And I see Rebecca dying to get

1 in as the developer, so.

2 MEMBER MOSS: Actually you raise good
3 questions, Sean.

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

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

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

20 Does that answer the question?

21 And I did want to briefly respond, if
22 it's okay, to how we came up with the top box

1 scoring methodology as opposed to some other
2 means of scoring these data. Most commonly it
3 would be a linear mean score between 0 and 100
4 because, of course, we recognize the concern that
5 you expressed.

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

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

19 And second of all, I looked at top box
20 versus linear mean scoring in terms of its
21 acceptability and comprehensibility to the
22 public. Because in anticipation of public

1 reporting, we know that top box scores tend to be
2 more digestible by consumers, and prior research
3 has shown that.

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

7 CHAIR MORRISON: Professor Berman.

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

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

19 MS. DEAN-WHITTAKER: What we are trying
20 to do in terms of public reporting is provide
21 data that is easy for the public to understand
22 and that is not -- and that is meaningful. So we

1 don't want to make our criteria too easy to meet,
2 and yet we don't want to make them too hard to
3 meet. We are interested in making information
4 available to the public.

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

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

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

20 Am I responding to you?

21 CHAIR MORRISON: And I -- yeah, and I
22 just have a clarifying question for Karen and

1 staff because I want to be clear in terms of our
2 deliberations. Are we talking about this as the
3 measure that's been proposed or are we talking
4 about how CMS reports the measure? Which are
5 very different.

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

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

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

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

22 MS. DEAN-WHITTAKER: We anticipate

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

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

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

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

20 Would you care to comment at all,
21 Rebecca?

22 DR. ANHANG PRICE: I think that covers

1 the landscape.

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

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

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

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

22 My question relates to the question

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

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

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

21 And so you will see when you talk
22 about risk adjustment for this, for these

1 measures, that region of the country is not
2 included.

3 CHAIR MORRISON: Deborah.

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

12 CHAIR MORRISON: Yes?

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

19 But at the same time, because we put
20 the spiritual with the emotional and it raises
21 reliability, doesn't necessarily mean that we're
22 getting what we need. And there are a lot of

1 items, I mean there are other questions --

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

11 MEMBER SCHROEPFER: I'll hold it then.

12 CHAIR MORRISON: Hold it. Thanks.

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

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

1 DR. ANHANG PRICE: Sure thing.

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

16 So we selected the N equals 200
17 threshold to balance those two concerns, to
18 establish a threshold that we thought would be
19 achievable for a fair number of hospices,
20 especially for pooling over four quarters, as
21 Deborah mentioned, while at the same time
22 recognizing that we wouldn't want to set it at,

1 say, N equals 300, which is which it is for
2 HCAHPS, for example, because that would be just
3 too many for many of the hospices nationwide.

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

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

12 Is that the right way to go, Karen?

13 MS. JOHNSON: Uh-huh.

14 CHAIR MORRISON: Okay. Christine?

15 MEMBER RITCHIE: It would influence my
16 vote.

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

1 PARTICIPANT: Second.

2 CHAIR MORRISON: Second.

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

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

8 Yeah, Linda? Microphone.

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

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

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

19 CHAIR MORRISON: We are.

20 MEMBER SCHWIMMER: Okay.

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

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

4 MEMBER MOSS: Point of clarification?

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

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

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

20 CHAIR MORRISON: We're dealing with the
21 same data but we're also dealing with how the
22 domains differ across them. And I think that is

1 the -- that is the problem of a complex -- not a
2 complex, a composite measure. Okay? Yes, it
3 would be different if we were -- but it is --
4 that's how I've been told to do it, Woody.
5 Sorry, Rebecca.

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

10 All in favor?

11 (Show of hands.)

12 CHAIR MORRISON: Anybody opposed?

13 So I'm going to need to see hands.

14 All in favor?

15 (Show of hands.)

16 CHAIR MORRISON: Okay, so the motion
17 carries.

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

1 Jean-Luc.

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

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

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

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

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

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

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

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

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

20 Jean-Luc.

21 MR. TILLY: Yes, that's right. Vote on
22 this one measure, treating family member with

1 respect, so it's 1 for high; 2 for moderate; 3
2 for low; and 4 for insufficient.

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

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

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

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

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

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

22 CHAIR MORRISON: Yeah, because we're

1 not in Chicago where you vote early and vote
2 often.

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

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

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

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

19 (No response.)

20 CHAIR MORRISON: Deborah, the floor is
21 yours.

22 CHAIR WALDROP: Okay. I'm going to

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

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

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

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

1 measure.

2 In terms of threats to validity, there
3 are exclusions that I mentioned in the beginning,
4 and those should be noted: again, people under
5 18, those still alive, those who died within 48
6 hours, and those who essentially whose care giver
7 was unavailable.

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

16 And I'll stop there.

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

21 MEMBER SCHROEPFER: I think at this
22 point I'm going to say, I'm going to say what I

1 think -- I just want to say that for the portion
2 we're talking about what is missing and what we
3 need to look at, rather than address this
4 particular.

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

8 Paul?

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

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

21 DR. ANHANG PRICE: Sure. So perhaps to
22 rephrase the question to be sure that we

1 understand. Is the question what happens in the
2 instance of a small hospice, particularly one
3 with perhaps an underserved population that's
4 more likely to have a lower response rate, when
5 they have very few completed surveys in the
6 course of a quarter or year? Is that the
7 question?

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

21 In terms of inclusion in an
22 accountability program for public reporting it is

1 more challenging because, because of the reasons
2 that we talked about from preventing those sorts
3 of responses from being included in public
4 reporting for any case for performance
5 initiatives that would be introduced at a later
6 time.

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

20 CHAIR MORRISON: Amy.

21 MS. DEAN-WHITTAKER: May I say
22 something?

1 CHAIR MORRISON: Sure.

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

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

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

20 So that is a constant problem that we
21 face. And it does have to do often with the
22 smaller providers who want to be included but for

1 whom the data may actually not be very good.

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

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

16 We are aware of it.

17 CHAIR MORRISON: Amy.

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

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

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

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

19 CHAIR MORRISON: Well, I'm going to ask
20 you guys if you want to address the -- if you can
21 address the response rate issue. And, again, I
22 think, you know, the issue -- I hear what you're

1 saying, Amy, but we can't rewrite the instrument
2 for them. So I think just tackling the response
3 rate and not issues around changing the
4 instrument. We have to deal with what's in front
5 of us, the response bias, not response rate.

6 DR. ANHANG PRICE: Sure thing.

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

17 We did, between the field test and the
18 national implementation of the survey, shorten
19 the survey substantially to try to, to try to
20 streamline it. We have found in other past
21 efforts that reducing the length of a survey by a
22 handful of questions did not substantially

1 improve response rate. So we don't really have
2 reason to believe that that would improve our
3 response rates here. In fact, the family
4 evaluation of hospice care survey that many
5 hospices across the country were using prior to
6 the CAHPS Hospice Survey are substantially
7 longer.

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

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

1 like to reduce it further.

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

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

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

22 MEMBER TATUM: A potential threat to

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

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

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

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

20 So we're going to vote on the
21 composites, yep, all together. Yep, all
22 together, Jean-Luc. And this is on the validity,

1 just to orient people to where we still are.

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

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

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

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

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

22 For me, one of the issues that I

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

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

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

21 CHAIR MORRISON: Deb, do you want me to
22 now turn that the measure developers? I've got

1 two questions there. One is the differences
2 across the three in terms of feasibility and what
3 that means? And then the second was the issue
4 about low resource hospices, yes.

5 CHAIR WALDROP: Yes.

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

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

1 experiment.

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

7 CHAIR MORRISON: Michelle.

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

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

19 MEMBER CAUGHEY: Just a follow-up
20 question just in a public health sense that the
21 marginal hospice agencies, even small additional
22 dollars may have impact on the availability of

1 these services. I don't know if that's outside
2 the scope. But it seems that feasibility, as we
3 rate that, I think we need to bring up that
4 issue.

5 CHAIR MORRISON: Christine.

6 MEMBER RITCHIE: So I might be missing
7 this, but under the committee pre-evaluation
8 comments there was a comment around a difference
9 in response rate by educational level of the care
10 giver. And I just couldn't find that data. I
11 just want to --

12 CHAIR MORRISON: So, Christine, is this
13 a question about whether --

14 MEMBER RITCHIE: Fifty-four? Thank
15 you, Amy. Page 54, if you didn't hear that.

16 CHAIR MORRISON: So is the question
17 here the feasibility of collecting from people of
18 low --

19 MEMBER RITCHIE: Yes.

20 CHAIR MORRISON: -- socioeconomic
21 status?

22 MEMBER RITCHIE: Yes.

1 CHAIR MORRISON: Okay. So I guess I'll
2 turn that over to the measure developers.

3 MS. DEAN-WHITTAKER: Well, I guess I
4 would have to say initially -- and I will ask
5 Rebecca to comment too -- that we do have a
6 problem with this but it's a problem that
7 addresses all surveys, the home health, the
8 hospital, and others as well. I am not aware of
9 but would be willing to certainly be enlightened
10 as to whether or not there would be a particular
11 issue with hospice.

12 But I am aware that we do have the
13 issue in general with surveys that rely on
14 literacy and with low literacy groups.

15 But perhaps did you have any comment
16 you'd like to add?

17 MEMBER RITCHIE: I was going to express
18 the same response, which is that it is of course
19 concerning to see higher rates in non-response
20 among groups that we would really like to hear
21 from in a survey like this. Unfortunately it's a
22 problem that affects every similar survey as

1 well.

2 We're fortunate to have these
3 different modes of administration which could
4 help with that a bit, again if the hospice elects
5 that mode of administration and can pay for it.

6 CHAIR MORRISON: Christine, are you up,
7 down? You're down.

8 Any last thoughts on feasibility
9 before we go to a vote?

10 (No response.)

11 CHAIR MORRISON: Jean-Luc.

12 MEMBER PURSLEY: One more question to
13 Debra. And that is you mentioned earlier that
14 there was a study that was done with a shorter
15 version of the survey versus a longer version of
16 the survey. And I was just wondering what the
17 sample size was for that and how many hospices
18 were involved in the assessment of the shorter
19 survey.

20 MS. DEAN-WHITTAKER: Well, the shorter
21 survey is the one that became the final survey.
22 The longer survey was a field test. And what we

1 did with the field test is we basically gave them
2 the kitchen sink. Everything we thought we might
3 want to include we had in there.

4 And the field test was done with a
5 smaller number of hospices. Now I -- do you know
6 offhand, Rebecca, how many there were?

7 DR. ANHANG PRICE: Sure thing.

8 MEMBER RITCHIE: It's irrelevant if
9 this is the shorter survey.

10 MS. DEAN-WHITTAKER: This is the
11 shorter of the two.

12 MEMBER RITCHIE: Never mind. Yeah,
13 it's irrelevant.

14 DR. ANHANG PRICE: Well, to one point
15 it might be relevant which is that that longer
16 survey, which is field tested among 33 hospice
17 programs with about 1,200 respondents had the
18 length of the survey range between about 68 items
19 to 72 items, depending on which setting of care
20 the decedent had been in. And the response rate
21 for that field test was higher than what we see
22 in national implementation, even for the parallel

1 mode of administration mixed mode.

2 Which is why I think that intuitively
3 we think that a longer survey means people are
4 less likely to respond. But we haven't found
5 that to be the case.

6 CHAIR MORRISON: Jean-Luc.

7 Cindi, is this a?

8 MEMBER PURSLEY: Just a quick comment
9 that our veterans' families get a much longer
10 survey.

11 CHAIR MORRISON: Jean-Luc.

12 MR. TILLY: Okay. So to vote on
13 feasibility for the cluster of eight measures,
14 select 1 for high; 2 for moderate; 3 for low; and
15 4 for insufficient.

16 The results are 0 voting high; 17
17 voting moderate; 6 voting low; and 0 voting
18 insufficient. The measure passes feasibility,
19 measures pass feasibility.

20 CHAIR MORRISON: Okay. We are on to
21 the final session of the final measure of the
22 final day. And, fortunately, I think this will

1 be relatively straightforward.

2 Deborah, usability.

3 CHAIR WALDROP: So that's my key to be
4 brief.

5 Okay, so just a couple thoughts on
6 usability and use. First of all, the measure is
7 not yet publicly reported but there is a plan to
8 create a compare website which I think could be
9 very useful.

10 And then the only other issue I wanted
11 to raise with the committee, we had a
12 conversation with the developers at the work
13 group meeting, but that's the notion of
14 unintended consequences. So bereaved care givers
15 will be receiving the survey two months after the
16 death of a loved one. And the only -- and this
17 again is from my research hat, the one that I
18 have to wear to the IRB -- which is you're going
19 to make people cry. Are you going to make people
20 cry? Is this going to be a problem for people?

21 And so we talked about what would that
22 be like to receive a survey two months after your

1 loved one has died. And we decided that the
2 benefits outweigh the burden of that.

3 And what I understood from our
4 conversation was that to date there have been no
5 responses that people said, Why did I get this
6 survey? or any harmful way. And they return any
7 distressed care givers back to the bereavement
8 program of the originating hospice.

9 So those are my thoughts on
10 feasibility and use.

11 CHAIR MORRISON: And, Deborah, you did
12 want to point out that this is already in use in
13 the hospice Quality Reporting Program, right? As
14 usability?

15 CHAIR WALDROP: Yes.

16 CHAIR MORRISON: She did.

17 Woody, go ahead.

18 MEMBER MOSS: Yeah, I just have a
19 question for those of you who are in the hospice
20 setting. So when people complete this survey do
21 you ever get calls to your bereavement
22 coordinators? And are you aware of any negative

1 consequences from that?

2 CHAIR MORRISON: Go ahead.

3 MEMBER CASS: Yeah. I think that we
4 do, we certainly do. And I think actually these
5 are good because it identifies people that really
6 need extra support. And while sometimes we may
7 be distressed by the results in a specific
8 survey, it does enlighten us that we need, we
9 need to be out there taking care of this
10 individual.

11 And again is that bias about do people
12 report more when they are in distress? But
13 either way, I think it's positive for us to be
14 alerted to the need for psychosocial
15 interventions.

16 CHAIR MORRISON: Amy.

17 MEMBER SANDERS: I think that the issue
18 of getting 47 questions about your loved one who
19 recently passed away probably has a lot to do
20 with the relatively low response rate. People
21 just look at it, think "I can't deal with it,"
22 and put it in the trash. I know that's what I

1 did.

2 CHAIR MORRISON: Cindi.

3 MEMBER PURSLEY: I concur with the two
4 previous comments.

5 CHAIR MORRISON: And, again, I want to
6 focus us on this is whether it's actually in use
7 and usability, rather than feasibility which is
8 what we just dealt with.

9 Amy Berman.

10 MEMBER BERMAN: So related to the
11 usability and use, just putting out there again
12 that this is not going to small hospices, so this
13 is the kind of exclusion to use and usability.
14 And understanding all of the existing constraints
15 and respecting those constraints, one other thing
16 to think about would be aggregating data over a
17 longer period of time in rural and frontier areas
18 so that we would have some sense, and the public
19 would have benefit of understanding, you know,
20 the relative quality of the local hospice.

21 CHAIR MORRISON: Thank you. Other
22 thoughts, comments?

1 (No response.)

2 CHAIR MORRISON: Okay. We're going to
3 go to the vote on usability. Jean-Luc.

4 MR. TILLY: To vote on usability and
5 use for all eight measures, select 1 for high; 2
6 for moderate; 3 for low; and 4 for insufficient
7 information.

8 The results are 8 voting high; 13
9 voting moderate; 2 voting low; and 0 voting
10 insufficient information. The measure passes
11 usability and use -- measures.

12 CHAIR MORRISON: Okay, guys, I was
13 wrong. We do have one more vote. Sorry.

14 So this one is on the overall measure.
15 And I just want to be very clear about what
16 you're voting for. You are voting for the
17 overall composite measure for only seven
18 domains. Okay? Because we put into the gray
19 zone the -- sorry -- treating family member with
20 respect. So that means that we cannot vote on it
21 as an overall endorsement.

22 So you are voting on seven measures

1 for endorsement: the communication; hospice care
2 training; timely care; emotional and religious
3 support; and getting help with symptoms. Did I
4 get them all? No. And the overall rating; and
5 the willingness to recommend.

6 Okay, does that make sense to people?
7 No puzzled looks?

8 And they're in front of you. Even
9 better. Hospice team information; timely care;
10 getting emotional and religious support; help
11 with symptoms; hospice training; rating of the
12 hospice; and willingness to recommend, Rachel
13 points out to me. So that is what you're voting
14 on.

15 MS. ROILAND: Paul, did you have a
16 question?

17 CHAIR MORRISON: I'm sorry. Paul.

18 MEMBER TATUM: Maybe it's just a brief
19 comment that I don't envy Karen the job of
20 explaining our rationale of dropping one measure
21 and not the other. And I didn't know if we
22 needed to comment further on that because from a

1 statistics standpoint I don't really understand
2 what you did, but.

3 MS. JOHNSON: It really is one of these
4 little funky NQF processes. So basically because
5 the one measure that you guys pulled out landed
6 in that gray zone of consensus not reached, our
7 rules are we don't ask you to do that final vote
8 for that one.

9 We will ask you to re-vote on that one
10 on the post-comment call. And there will be a
11 final vote on that one at that time.

12 CHAIR MORRISON: Paul, anything that
13 follows NQF process she can explain beautifully,
14 so don't worry about that.

15 All right, so yea or nay, folks, up or
16 down.

17 MR. TILLY: To answer the question for
18 the seven measures under consideration, does the
19 measure meet NQF criteria for endorsement? So 1
20 for yes; 2 for no.

21 The results are 22 voting yes; 1
22 voting no. The seven measures are recommended

1 for endorsement.

2 CHAIR MORRISON: Congratulations,
3 folks. We are done with all of the measures.

4 Just before we go to lunch, and you
5 guys have really, really deserved it, I need to
6 open up the phones for public comment and then
7 turn to the room.

8 So, Operator, if you could open up the
9 phones for public comment. And just to remind
10 people, public comment is on the events that
11 happened this morning, not events that happened
12 yesterday that you might have missed.

13 OPERATOR: Thank you. At this time to
14 make a public comment please press star one on
15 your telephone keypad.

16 At this time there are no public
17 comments.

18 CHAIR MORRISON: Fantastic.

19 So then let me turn to the back of the
20 room for public comment. And could I ask you to
21 come up to the mic, if you have one or two.

22 DR. SPENCE: Okay. All right, thank

1 you.

2 First of all, I have a huge amount of
3 empathy and admiration for the team that put this
4 together.

5 CHAIR MORRISON: Carol, I'm sorry, can
6 you introduce yourself?

7 DR. SPENCE: Oh, I'm so sorry. I was
8 here yesterday. Okay. All right.

9 Carol Spence, National Hospice and
10 Palliative Care Organization.

11 I think it's referred to in the
12 submissions briefly, but we had the precursor to
13 the CAHPS Survey, the Family Evaluation of
14 Hospice Care, which is why I have so much
15 admiration and respect for what the CAHPS team
16 and RAND have produced.

17 I just want to make one comment
18 specific to the response bias issue. And forgive
19 me, I'm not 100 percent familiar with everything
20 that goes into the file that is submitted to the
21 vendors. I know there is decedent information.

22 One of the things that we did with the

1 demographic information that was collected was,
2 in our reports of course we reported it out, but
3 we pointed out to hospices that they should
4 compare the demographic information of the
5 respondents to their patient census, which they,
6 they could easily do, to look at who was not
7 responding. So, you know, diagnosis in
8 particular group, but age for a number of
9 reasons.

10 Again, our survey was not for
11 accountability as this one is, but it was for
12 quality improvement. So for hospices to look at
13 were there care givers -- was there a group of
14 care givers who were not responding? You know,
15 were they an older group, a particular ethnic
16 group, and that meant they had to do something
17 about their survey that they, you know, that they
18 could. But also to look at if they have a huge
19 particular, you know, cancer population but it
20 was the debenture people who are returning the
21 survey, et cetera, et cetera.

22 So I think this is not perfect but it

1 is one way to look at response bias and in a way
2 that could help the hospices, you know, know who
3 they're reaching, who those patients are whose
4 care givers are returning the survey and who
5 they're not is a piece of the puzzle.

6 MS. SINCLAIR: Hello. Stacie Sinclair
7 from the Center to Advance Palliative Care. I
8 just wanted to thank you again for your
9 thoughtful work this morning.

10 As the committee begins or prepares
11 for its discussion on measurement gaps in the
12 field this afternoon, we just wanted to highlight
13 that there remains a gap in quality measurement
14 or quality reporting for small hospices. Data,
15 including a recent article from Melissa Aldridge
16 demonstrates that they tend to perform poorly on
17 quality metrics.

18 And as you established during this
19 morning's discussion, CAHPS may not be the
20 appropriate measure due to the high cost burden
21 on providers and the low validity in response
22 rate. Therefore, this was just something that we

1 wanted to urge you to keep in mind for this
2 afternoon's discussion.

3 Thank you.

4 MR. JEFFRIES: Hi, Sean. Craig
5 Jeffries. I am with Compassus. We're a national
6 provider of hospice and palliative care.

7 And I just wanted to reinforce I think
8 comments that were made both on some of the
9 preliminary calls and here today. I'm
10 specifically thinking of the 0216, 0215, but it's
11 applicable to others. But just to reinforce that
12 some of these measures deserve cost setting
13 consideration. They're very good measures. They
14 could be utilized by other physician specialties.

15 So I know that's not really in the
16 scope of what you're doing today but I think if
17 the record could indicate that this is a topic
18 that came up and important for further
19 consideration.

20 Thank you.

21 CHAIR MORRISON: Well, I think now --
22 So I think what I'm hearing from Karen is I think

1 what we're going to suggest is a short working
2 lunch so people can get out of here, rather than
3 a regular lunch. So why don't we take 10 minutes
4 to get food and then come back and we can start
5 on the agenda for this afternoon.

6 And, George, I see a hand.

7 MEMBER HANDZO: Sorry. I haven't
8 gotten this card thing down at all.

9 CHAIR MORRISON: No worry.

10 MEMBER HANDZO: Are going to make any
11 attempt or can there be some attempt to kind of
12 coordinate rides to airports?

13 CHAIR MORRISON: Rachel.

14 MEMBER HANDZO: Yeah, I didn't want to
15 pick on Rachel right out of the box. But I
16 thought that's where it was going.

17 MS. ROILAND: No, that's okay.

18 So when we adjourn the meeting -- and
19 thank you, Tracy, she's made the suggestion that
20 if folks are heading straight to the airport
21 right after the meeting we would just like you to
22 sort of meet under the clock over there and you

1 can try to coordinate cabs together.

2 And, also, if you are wanting to try
3 to take the Metro to the airport we're very close
4 to McPherson Square. And the Blue Line train
5 there will take you directly to the airport as
6 well. So that's another option.

7 CHAIR MORRISON: That goes to National.
8 The Blue Line goes to National.

9 MS. ROILAND: Sorry, yes. Yes. I
10 apologize.

11 CHAIR MORRISON: Dulles is a taxi.

12 Let's break for lunch rather than
13 getting into Washington transit discussions.
14 Thank you.

15 (Whereupon, the above-entitled matter
16 went off the record at 12:35 p.m. and resumed at
17 12:52 p.m.)
18
19
20
21
22

1 A-F-T-E-R-N-O-O-N S-E-S-S-I-O-N

2 (12:52 p.m.)

3 CHAIR MORRISON: So we're going to get
4 restarted. This is actually the fun part of the
5 day and a half. And as soon as Karen comes back,
6 we will get going. Actually, Rachel will take
7 over. Rachel?

8 MS. ROILAND: All right. Hi,
9 everybody. Just while you're eating, I'm
10 actually going to walk around and ask you to take
11 a little piece of paper out of this pink cup, so
12 we can divvy up the two- and three-year terms.
13 So it's just random happenstance about which one
14 you get, and that will be what we'll go with
15 moving forward.

16 MS. JOHNSON: So for Bob and Alice on
17 the phone, we are sending around the cup for
18 people to do the random selection of terms. And,
19 Bob and Alice, we will figure out how to randomly
20 select for you. So stay tuned.

21 Okay. It looks like pretty much
22 everybody has taken their piece of paper from our

1 cup and our hat. Just a reminder that you will
2 have an option, once your terms are up, if you
3 want to re-up for another term, that would be an
4 option open to you. So two years from now, we'll
5 start talking to a few of you about whether
6 you're interested in that option.

7 So with that -- yes?

8 MS. ROILAND: So what I'll ask you to
9 do, just for the sake of time, if you could write
10 your name on the little slip of piece of paper
11 that you took and just drop it off with me before
12 you leave today, I'd really appreciate it. And
13 then I'll randomly select for, Jean-Luc and I
14 will randomly select for Bob and Alice and
15 Robert. So just so we're all clear about that.
16 Thank you.

17 MS. JOHNSON: Great. Okay. So this
18 part of our discussion is actually probably going
19 to an interesting and fun part for you guys, and
20 it's not going to be as hard of work as what
21 you've done in the last day and a half, so that's
22 a good thing.

1 What we want to do is have a
2 discussion about framework and gaps. So let me
3 put it into a little bit of context for you.
4 Yesterday, I showed you a draft framework. I
5 mentioned a framework that was done in 2006 by
6 predecessor groups, so we have that one. You may
7 know of other frameworks that might work for,
8 again, a measurement framework, a way to think
9 about what measures we have, what measures we
10 need. So we want to talk about that a little
11 bit.

12 We also want to talk about what are
13 the gaps in measurement, and I think one of the
14 things we have to -- and you guys can guide this
15 -- do we need to split out end of life versus
16 palliative or is it okay to talk about everything
17 together? You guys will help us understand that,
18 in terms of gaps.

19 I threw up a few questions here on the
20 screen just to consider. We don't have to go
21 through these in order. How should the draft
22 measurement framework be modified? So, again,

1 with that, maybe we go back to the original one.
2 Maybe you know of something completely different,
3 so that's fine.

4 What are the gaps? What are our
5 measurement priorities in terms of, so not just
6 talking about what the gaps are but, you know, if
7 we had to tackle something sooner, rather than
8 later, what would be the ones that would need to
9 be done first? So that's what I meant by
10 priorities.

11 And to some extent, are you aware of
12 other measurement efforts? So, you know, if
13 things are already in the works that you know
14 about, let us know. We don't want people going
15 off and spinning wheels and reinventing wheels if
16 there's something already going on, and maybe you
17 guys know about this. And, quite frankly, maybe
18 you're doing some innovative things in your own
19 shops, and maybe those need to come to NQF. So
20 that's what I'm getting at there.

21 So this is going to be a bit of a
22 freeform conversation. So who wants to start us

1 out? It looks like Paul.

2 MEMBER TATUM: I'm so glad this
3 picture just came up because this is what I
4 wanted to address. And I'm here partly thanks to
5 the American Geriatric Society so putting my
6 geriatrician hat on. And, Karl, you might speak
7 to this from the long-term care side of things.

8 One of the things missing on settings
9 of care is the assisted living facility
10 community. And Joanne Lynn on, I believe, the
11 Diane Rehm Show a year or two called assisted
12 livings the Wild, Wild West in terms of, you
13 know, oversight and regulation and quality
14 measures in that domain. And so I think we
15 should think about adding that on to our settings
16 of care, and I think it's a critical area for us
17 to think about what is quality there.

18 MS. JOHNSON: Okay. Woody?

19 MEMBER MOSS: So, actually, Christine
20 and Arif can speak to this even more
21 knowledgeably than me, but the American Academy
22 of Hospice and Palliative Medicine has a Measure

1 What Matters Most to patients, and I think some
2 of those measures would be very good ones for us
3 to look at with the idea that people have
4 criticized measures sometimes as being
5 convenience measures, what's easy to measure but
6 what's important to measure. So I just, there
7 are ten of those in the Measure What Matters Most
8 and we could look at them.

9 MS. JOHNSON: Right. Actually, a few
10 of those are NQF-endorsed measures that you
11 looked at this time around, but some of them,
12 you're right, they're not. Amy?

13 MEMBER SANDERS: So I have two
14 questions, one of which I think is probably very
15 specific and the other one is a little bit more
16 wide-ranging. The first one, the more specific
17 one, at least in my head, is whether the change
18 by CMS effective at the beginning of this
19 calendar year to begin reimbursing for advanced
20 care planning discussions with patients is
21 something that is currently addressed in any sort
22 of measure anywhere. Maybe that's not as

1 specific as I thought it was.

2 And then also what the sort of group
3 feels about the utility of disease-specific
4 measures or syndrome-specific measures. A lot of
5 measures are focused on cancer, but people die
6 from a lot of other things. So, you know, if
7 somebody is dying from COPD or, you know, my
8 personal area of interest, which is dementia,
9 where the care-planning can go for years, if not
10 even, you know, longer than a decade and how that
11 sort of changes the way that measures would be
12 developed.

13 I know the American Academy of
14 Neurology does have a measure currently in
15 development, or in update, related to advanced
16 care-planning discussions for patients with
17 dementia.

18 MS. JOHNSON: Does anybody want to
19 respond to Amy's questions? I don't think that
20 was directed to me necessarily, right?
21 Christine? Okay. So you weren't -- I'm just
22 asking if you were responding to Amy or --

1 MEMBER RITCHIE: It's related to what
2 Amy Sanders said, which is -- and we already
3 addressed this a little bit over the past two
4 days, which is that we do have a lot of measures
5 that are focused on specific conditions and not
6 multiple chronic conditions, and this is becoming
7 increasingly a point of concern, as I now am
8 engaged in population health at my institution
9 and seeing a lot of things being applied to the
10 inappropriate population because they just happen
11 to have that one condition in the mix.

12 MS. JOHNSON: Okay. Amy Berman?

13 MEMBER BERMAN: So I guess two things.
14 One is around the notion of palliative care in
15 general. Today, we can't really measure whether
16 somebody got a palliative care consult. We have
17 challenges getting basic information, which would
18 then be able to tell us against claims data
19 whether or not doing those things has an outcome
20 around value. And we're all moving toward value.

21 I think we need to understand what is
22 specialty palliative care, when that has been

1 applied, versus when primary palliative care may
2 be offered, and we need to look at both and
3 whether or not, as we create competence in a
4 broader workforce to deliver palliative care, and
5 the purpose of their appointment is to deliver
6 that palliative care, whether they're successful
7 in doing it, versus when experts are brought to
8 bear and whether or not -- when they can't manage
9 that care, then the field of palliative care is
10 deployed and what is the value proposition of
11 that.

12 So we're constantly conflicted. As a
13 matter of fact, I've heard that some people
14 measure, for example, referrals to palliative
15 care. Why do they measure referrals? Because
16 they can't measure whether or not they got a
17 palliative care visit. This is kind of absurd
18 when we talk about palliative care as being one
19 of the major areas we want to measure, and we
20 can't measure even the most basic data there.

21 The other thing, I guess I'm going to
22 go to the center of the circle, and I could talk

1 about a lot of things, but I'm going to talk
2 about the family. And patient and family are at
3 the center. If this were a pediatric guidelines
4 meeting, we would have talked quite a bit around
5 family aspects. There is going to be a report
6 coming out by the National Academy of Medicine
7 around family caregiving in older adults. Some
8 of those recommendations may be very helpful as
9 you develop out the work because the family
10 caregiving issues are big and largely
11 unaddressed. We don't know who the caregiver is.
12 It's not identified in the record. We don't ask
13 whether somebody is willing to do something. We
14 make assumptions, and the system falls apart if
15 we don't do a good job.

16 So the family caregiver aspect I think
17 is one of those great opportunities for NQF to
18 address.

19 MS. JOHNSON: Arif?

20 MEMBER KAMAL: Yes. As Amy so
21 brilliantly and eloquently said, some of these
22 things -- one of them, and Christine and I and

1 several of us have thought about this, is the
2 denominator issue in palliative care, that as
3 change agents for healthcare, which, in a lot of
4 ways, palliative care, as a field and as a
5 discipline, has been anointed the change agent in
6 a lot of different ways. Fix the 30-day
7 readmission rate, who's going to do that? Well,
8 it's not the cardiologist, right? It's the
9 palliative care clinicians that are often tapped
10 to fix this problem for us.

11 So if we are willing to embrace this
12 idea of change agents, that means it requires
13 making an impact above and beyond the patients we
14 actually see face-to-face, right? So there's
15 what do we do as a specialty? But if we ask
16 ourselves the question who within NQF or across
17 the healthcare quality environment is developing
18 measures for serious illness and critical illness
19 that addresses these domains, that may fit in
20 other specialties per se that we never see, are
21 others picking up the torch and doing that, or is
22 that really the responsibility of our discipline?

1 In addition, in terms of specific
2 domains that I think we're missing, from some
3 work that we've done on systematic reviews of
4 quality measures, you know, the domain of
5 cultural and social aspects of care, I mean, it's
6 just two big empty boxes and spiritual -- other
7 than do a spiritual assessment. So there are
8 important gaps that exist.

9 In terms of new domains, we know that
10 financial toxicity in multiple different surveys,
11 at least in cancer patients, is either number two
12 or number three of their concerns. And number
13 one and number two tend to be sort of the future,
14 and how am I and my family going to sort of deal
15 with this experience issue? Number two seems to
16 be symptoms, and number three, not that far
17 behind, is financial toxicity. So I wonder if we
18 should bring that into our wheelhouse of things
19 we feel comfortable addressing.

20 The other thing is when people ask us
21 what we do and we say the patient caregiver is
22 the unit of care for us, I look at this and I

1 say, well, we don't have an imperative or
2 marching orders to address anything related to
3 the caregiver, which I think has, ultimately,
4 fiduciary and reimbursement implications down the
5 road as well, in terms of how I spend my time
6 with a patient. I bill the patient, yet I'm
7 supposed to focus on a caregiver, yet there are
8 no quality measures that say what I'm supposed to
9 do and how often I'm supposed to do it.

10 And then, lastly, some have talked
11 about the triple aim everybody knows, but some
12 have written actually in the family medicine
13 literature about the quadruple aim around this
14 concept of preserving our workforce. Many know
15 that there is a burgeoning area of work around
16 resiliency training in our field. We estimate
17 that, one, that our burnout rate in our field is
18 higher than any other field that we know of, one;
19 two, that we expect to lose 50 percent of our
20 workforce in the next ten years with the primary
21 reason, other than retirement, being burnout, as
22 stated in our survey; and that, three, the

1 proliferation of resilience programs and other
2 things within palliative care has been slow.
3 It's slow across all of healthcare, but I think
4 it's an important thing here. I think last night
5 at dinner we talked about a structural or process
6 measure to say what we do is tough, and we need
7 programs or something in place to address that.

8 MS. JOHNSON: Okay, great. Karl, I
9 think on this side.

10 MEMBER STEINBERG: So something -- I
11 think there's a little bit of a gap as far as
12 functional measures, and I don't know if
13 functional should be one of the domains of care,
14 but I mean we have physical, and I guess
15 functional impairment sort of would go under
16 that.

17 But, I mean, that impacts so heavily
18 on things like prognosis, and so I think that's
19 something that -- and of course, there are
20 measurements, there are measures for functional
21 status like on the MDS and so on. And I guess
22 they're going to be improved coming up in the

1 near future, but as far as treatments that people
2 are getting and how functionally impaired they
3 are, let's say if you're getting chemo and those
4 kinds of things.

5 And I think there is a difference
6 between palliative care and end-of-life care, but
7 -- there might be some measures that apply to one
8 and not the other. But I think they're similar
9 enough that it's reasonable. Us sitting around
10 the table, we're dealing with both.

11 MS. JOHNSON: Okay. Sean?

12 CHAIR MORRISON: I apologize that I
13 have to leave early because I gather this is
14 going to be a fascinating discussion. So just a
15 couple of comments before I go. In thinking
16 within the measurement framework, when I look at
17 this measurement framework that has end-of-life
18 care, palliative care, and bereavement care, what
19 it strikes me a bit is this is a very healthcare-
20 specific model and that patients and families
21 don't classify themselves as being "at the end of
22 life," and we are terrible at doing that. And

1 palliative care assumes that that's a specialty-
2 driven care.

3 And what I would much rather see is
4 this framework be around serious illness because
5 that would bring in geriatrics, it brings in
6 pediatrics. It's non-specialist care, and that
7 would encompass all of this. And part of the
8 problem is that we've never been actually able to
9 define that denominator. But I think we are
10 getting much better at it. Amy and Christine
11 just recently published a very good paper that
12 could identify a population of patients with
13 serious illness with very specific attributes
14 that could be relatively easily obtained from
15 administrative data if the necessary changes were
16 made.

17 And I think, Karen, within that
18 context, then you have both setting-specific,
19 stage-specific, specialty-specific measures that
20 would apply. But I think we really have to get
21 outside of this healthcare or medical box of how
22 we think about the population at risk.

1 And then bereavement care, quite
2 honestly then, as Amy said, comes down onto the
3 family framework, rather than the patient
4 framework, unless -- I haven't figured out how to
5 have seances yet, but George will work on that
6 with me. But I think that that fits in in terms
7 of the family care, so that's the first thing.

8 The second thing which has been
9 ignored which, again, is a very, very high
10 priority, at least for me, is to start rethinking
11 about the quality metrics that we see for this
12 patient population around patient safety. We
13 have narrowly focused patient safety on acts.
14 We've narrowly focused patient safety on
15 infection. But quite honestly, I think pain
16 belongs in the patient safety area. I think the
17 poor transitions belong under patient safety, and
18 I think there are a wealth of measures that apply
19 to our patients and families that really should
20 be under that much broader rubric and shift out
21 of "the serious illness quality metric" because
22 they really are adverse outcomes that have strong

1 implications for the safety of this population of
2 patients. And I think, from my perspective, we
3 have to start advocating for that gap within the
4 patient safety rubric or framework. So I will
5 thank you.

6 MS. JOHNSON: Thanks. George, yours
7 is up.

8 MEMBER HANDZO: Thank you. Two
9 things, one on the framework and then on the
10 gaps. But I've already confessed my involvement
11 with NCP, but I really like the eight domains of
12 NCP, and I think it's well-established now and
13 well-vetted and all of that, and I think that,
14 for me, is a very helpful framework to see this.
15 So just that.

16 And so within that, even going back,
17 it looks like, and Tracy and others have talked
18 about this, where, obviously, if you take even
19 four domains, if you take Cicely Saunders and the
20 original four, you're heavy on the physical, not
21 that there's not a lot to do. I'm not trying to
22 say that. But the social and the spiritual and

1 emotional and spiritual are virtually absent.

2 And so things like -- I mean, we have
3 in spiritual care a validated screening tool or
4 more or less validated screening tool for
5 spiritual distress. It's a three-question tool.
6 So we don't know -- to Amy Berman's point, we
7 don't know what the real prevalence of spiritual
8 distress is in any healthcare population,
9 including this one.

10 So screening and then the way we've
11 done it, the kind of screening, assessment,
12 treatment continuum, I mean, the beliefs and
13 values is great, but it needs to be paired, like
14 dyspnea and pain, with a so what, so you have a
15 discussion: so what? There needs to be a way to
16 move on from that like the rest, and we need to
17 move into those areas. And both for emotional
18 and spiritual, I think, are both aligned there.

19 So, I mean, I think I would start with
20 a follow-up to beliefs and values, and I'd start
21 with a basic kind of where we are with everything
22 else, let's screen for it and find out what's out

1 there and then validate the literature from
2 there.

3 But it's a -- I always laugh when
4 people say, can we do a gap analysis on spiritual
5 care? Because it's a gap. It's all a gap. Pick
6 your place, it doesn't matter.

7 MS. JOHNSON: Debra?

8 MEMBER WIEGAND: Thanks. I just
9 wanted to comment that it seems like a population
10 that's missing from measurement is pediatric and
11 neonatal palliative care and end-of-life care.

12 MS. JOHNSON: I've kind of lost track.
13 Over here, Gregg? Christine?

14 MEMBER VANDEKIEFT: So I completely
15 agree with everything Amy and others have said
16 about having the patient and family at the center
17 and making that our focus, but what I'm going to
18 say almost goes counter to that, which is one of
19 the things that we've struggled with, is how to
20 extract meaningful data in the era of the
21 electronic health record, and I don't know how
22 much rating or evaluation or measurement of

1 various vendors or products has been done and
2 whether something of that nature would actually
3 be beneficial to where you could actually look at
4 the Epics or the MEDITECHs and see what can we
5 extract, how can we work them, and grade them and
6 evaluate them in our own way? Maybe that's being
7 done; I don't know. But it just occurred to me
8 as something that's such a great challenge in the
9 field. It might move us forward.

10 MS. JOHNSON: John, is that a -- okay.
11 Christine?

12 MEMBER RITCHIE: So just as an add on
13 to what was said by Arif and Sean around safety
14 and financial toxicity is treatment burden and
15 treatment-related harm.

16 MS. JOHNSON: And what was that last
17 word? I'm sorry. Treatment-related harm. Got
18 it. Let's see. Tracy?

19 MEMBER SCHROEPFER: So two things that
20 I'd like to talk about. One is culture. And I
21 think in terms of this, so I work a lot with
22 tribes, Amish, different populations in

1 Wisconsin, and work closely with them around end
2 of life, and what comes up a lot is that using
3 hospice, palliative care, hospitals is very
4 difficult for them because their cultures are not
5 honored; their ways of life are not honored.

6 Self-determination, familial determination, most
7 of the time or a lot of the time for some of the
8 cultures, is more correct. And so feeling like -
9 - and what a lot of the tribes that I've done
10 qualitative interviews with, et cetera, feel that
11 they can't ask questions of doctors or nurses or
12 even social workers because they feel like people
13 think they're stupid and dumb, and part of that
14 has to do with the lack of time that's spent with
15 them and also recognizing that their language,
16 like, for example, with the Hmong, we have a high
17 Hmong population, and I've been working with them
18 for about seven years, and there's not a word for
19 cancer in Hmong. It's not that simple. Chemo,
20 radiation.

21 So feeling like we have a lot of work to do there
22 if we're going to look at quality at end of life

1 and with serious illness.

2 I think the other thing is
3 environment. We don't think a lot about
4 environment. I just want to give you an example,
5 and then I promise I won't talk a lot. The
6 example is, with one of the tribes, hospice is
7 pretty -- the reservation goes very deep, and
8 where people live is deep in the reservation.
9 And so, you know, the elders often talk about,
10 yes, we start with hospice, but we don't stick
11 with hospice, and the reason is because we're so
12 far in, we get scared, the families do, that,
13 should something come up, that nobody could get
14 there quick enough to relieve the pain or
15 whatever. So they'll start with hospice, but
16 what they'll end up doing is going in the
17 hospital. And we've talked about tele-medicine
18 and different things.

19 But in terms of the hospital, we have
20 a hospital in Wisconsin that being aware that the
21 elders most likely will end up in the hospital,
22 the issues for this particular tribe are the need

1 to burn sage at the end of life. Okay. That's
2 not good because you could blow the hospital up,
3 right? Oxygen tanks and stuff, yes. And they
4 understand that. The need to chant, the need to
5 drum, the need to have family. And family is so
6 different: for many populations it's not the
7 immediate family; your 20th cousin is family. So
8 where are the rooms large enough? Windows.
9 Several of the tribes, the need to open the
10 windows so the spirit can leave. So this
11 hospital actually created a room away from oxygen
12 and insulated it so the drumming, et cetera.

13 So I know there's so much to do, but
14 we often say why don't people use hospice or
15 hospice facilities or hospitals, et cetera, and
16 part of it is that the environment for them --

17 And then the last thing is, and this
18 kind of gets to the spiritual, is for doctors,
19 and this is down the line, thinking about how we
20 measure a more integrative care in terms of, for
21 the Hmong is the shaman and the need for the
22 shaman to work with the doctor. That's really

1 important. Curandero for certain Latino
2 populations, a traditional medicine man for some
3 of the tribes. And what I've heard is there was
4 one tribe up north, Bad River, where the doctor
5 there honored the fact that when an elder got
6 cancer and had tumors, they first had to work
7 with the traditional medicine man to spiritually
8 be ready for the chemo and the radiation. This
9 was the only doctor that would wait and not say
10 things to the patient about you're crazy; that's
11 going to take two weeks, and your tumors.

12 So just thinking that there's so much
13 I could go on and on and on about the importance
14 of culture. But I think it is something that we
15 mention, but we don't do a lot with, and it
16 really does end up that people feel very
17 alienated.

18 My last thing I'll say is something so
19 simple as one of the Hmong leaders said to me one
20 day, we had been working together for a number of
21 years, and he said, "So now I can ask you this
22 question because you won't think I'm dumb," and

1 so Feluck said to me, he said, "Tracy, when we go
2 to UW Hospital, why do we only get students?" He
3 said, "Why the Hmong just get students?" and I
4 explained to him it's a teaching hospital and
5 that everybody gets students. Nobody had ever
6 explained that, but he also had been afraid to
7 ask it because it would just be another stupid
8 question by a Hmong person. And that's his
9 language, not mine.

10 So I just want us to also bear in mind
11 the importance of culture when we think about
12 this in moving forward because it's embedded in,
13 we talk about pain, we talk about symptoms,
14 sometimes when we're measuring things we're not
15 measuring them correctly because culture is not
16 being taken into consideration, even down to pain
17 charts where an elder told me you can have all
18 those faces you want; we'll always choose the
19 middle because it's stoic, and that's who we are.

20 So that's it. I'll shut up now.

21 MS. JOHNSON: Cleanne?

22 MEMBER CASS: I'm just curious about

1 process. Do we develop a suggestion for a
2 measure, and then a measure developer picks it,
3 up, or how does this work? We can sit here and
4 have wonderful ideas, so should we be structuring
5 our thoughts a little bit more around what
6 they're interested in, or how does that work?

7 MS. JOHNSON: Ideally, yes, you guys
8 would mention and kind of come to some conclusion
9 about the priorities, and somebody would pick it
10 up. That doesn't always happen, but I do think
11 they are paying at least some attention, knowing
12 that different developers have different goals,
13 depending on the developer, depending on who's
14 funding the development, et cetera. So I think,
15 at least right now, the best we can do is get
16 things on the table and get them out there.

17 That said, and I don't know, Marcia,
18 if we need to talk anything about the work that
19 NQF is doing in the prioritization. Is that
20 something that would fit in here?

21 MS. WILSON: It's a great question,
22 and I'll just make a brief comment about NQF has

1 been going through some strategic planning
2 exercises, and one of the things we're looking at
3 is prioritization of gaps, identifying gaps in a
4 more organized fashion. Another activity I would
5 mention that's going on is something, the NQF
6 measure incubator, which is a new enterprise for
7 us, relatively new, where, as you know, NQF does
8 not develop measures, but we know a lot of people
9 who do. And so we've taken on a role, this NQF
10 incubator project, and there are others in the
11 room I know who could speak to this, as well,
12 where we're trying to facilitate or coordinate
13 people who have measure ideas, measure data,
14 funding for measures, and measure developers, who
15 have the technical expertise that people can come
16 forward and say we're interested in developing
17 this measure, and we help coordinate those
18 relationships and put people in touch. It's a
19 relatively new program, but we have a couple of
20 measures who are going through this process right
21 now. We hope it's going to work. One of the
22 measures is a patient-reported outcome for COPD,

1 and another, we're also working on a contract,
2 the Robert Wood Johnson Foundation has funded
3 PatientsLikeMe, if you're familiar with that
4 platform. It is a web-based patient-sharing data
5 platform to look if that data perhaps could be
6 used to develop patient-reported outcome
7 measures.

8 And one thing I will say, we've had a
9 lot of interest in this incubator project, and
10 most of the interest has been in developing
11 patient-reported outcome measures. So stay tuned
12 for there. But we're hoping that might
13 facilitate some measure development more quickly,
14 more efficiently. We hope. It remains to be
15 seen. But also looking at our gaps because we
16 get gaps from you all, we get gaps from all of
17 our committees, how can we present those gaps in
18 a more organized way so people can say, okay, I'm
19 starting to see the common theme here; I'm
20 starting to see the priorities. So it's very
21 much on our radar.

22 MS. JOHNSON: And I would add to that

1 we may have a little bit of time before 2:00 to
2 talk about next steps beyond just this
3 endorsement project. We call them off-cycle
4 activities. So one possibility for an off-cycle
5 activity might be to put some more meat around
6 these bones and do a little bit more focused job
7 than what we're able to do in an hour around the
8 table. This is right now kind of the
9 brainstorming thing. It's the brain dump.

10 So that's one option that we could
11 potentially go for.

12 MEMBER CASS: I feel like if we're
13 going to get excited about something, we want to
14 make sure it's going to go somewhere. That
15 should try to focus us, help us.

16 MS. JOHNSON: I have kind of lost
17 track of who said what, so I'm just going to kind
18 of go back and forth this way. So I think Laura.

19 MEMBER PORTER: Thank you. What I
20 want to bring up is something that we talked
21 about at dinner last night also. It seems to me
22 that when we refer to palliative care in the

1 group, we're talking about end-of-life care and
2 that there really isn't a differentiation between
3 palliative care and end-of-life care. And I
4 know, as a stage 4 cancer survivor, I think that
5 if I had had palliative care early in the
6 process, I would have been spared a lot of the
7 horrendous side effects that I went through.

8 And so my issue is that all of the
9 measures that we looked at were basically end-of-
10 life measures and hospice measures, but are we
11 going to look at palliative care just as
12 palliative care, or do we, like somebody
13 suggested last night, need to change what we call
14 it? I mean, I don't know if that's our role,
15 but, I mean, it's kind of -- that's just my
16 concern because I thought when I came here that
17 it would be clear that there was a difference,
18 and I was kind of disappointed that I didn't find
19 a difference between palliative care and hospice,
20 that they were used interchangeably.

21 MS. JOHNSON: Okay. Amy Sanders?

22 MEMBER SANDERS: So a couple of things

1 once again. I think that what is needed is a
2 series of sort of knowledge and attitude surveys.
3 I think that out in the world what is meant by
4 palliative care, hospice care is not well
5 defined. People often conflate the terms, I
6 think perhaps to a greater degree than is sort of
7 current within the borders of the hospital. I
8 think we're beginning maybe to separate those two
9 terms, but that's new. And so knowledge,
10 attitudes, understanding, and obviously it needs
11 not just to be about the physical and the medical
12 but the cultural, what are the barriers to people
13 accepting the offer of help and assistance in the
14 form of palliative or hospice care?

15 And I think that we need to survey
16 ourselves, as well. I think that we don't have a
17 universal understanding of the nomenclature that
18 we all use, and when we use those terms, we may
19 mean one thing, but the person or group to whom
20 we're speaking understands a different term. So
21 I think maybe really taking things back to first
22 principles, dealing with nomenclature, would be

1 important but probably some sense of what
2 actually the understanding abroad in the world is
3 would be a necessary first step.

4 And I would also like to compliment
5 whoever made this diagram that's currently up. I
6 think it was somebody on this group who sort of
7 put this diagram together, and I yesterday in my
8 study immediately copied it down. And I think
9 it's a really, really helpful diagram, so kudos
10 to whoever did that.

11 MS. JOHNSON: Thanks, Amy. I'm going
12 to skip over to Deborah.

13 CHAIR WALDROP: Thank you. So I have
14 a couple of disparate contributions hopefully.
15 First of all, I'm looking at the diagram, to tag
16 on to what Amy said, and I think, in terms of
17 domains of care, one of the pieces that's really
18 missing is decision-making, and so decision-
19 making not just around end-of-life decisions but
20 across the course of an illness trajectory, and I
21 would say across the course of a specific illness
22 trajectory. So it's very different when you have

1 end-stage renal disease or COPD than cancer, and
2 I think we need to think about the decisions
3 along the course of illnesses and help people
4 with symptom exacerbations and what the end
5 stages are going to look like in different
6 disease trajectories. That's thought number one.

7 Thought number two is also in terms of
8 settings of care, it's big boxes: it's inpatient,
9 outpatient, home, hospice, and skilled nursing.
10 Assisted living, as Paul says, needs to be there,
11 but so does emergency medicine. I think the
12 marriage of emergency medicine and the crisis
13 that families find themselves in when they don't
14 know what dying looks like, the call to 911 that
15 maybe is the right thing to do. Maybe ED is
16 where the person needs to go, but maybe it isn't.
17 And if we could meet people where they are, I
18 think there's a real sort of emerging literature
19 and emerging study of palliative care in the
20 emergency department, but I would like to take it
21 into the field and think about it there.

22 And I think I'll stop there. Thank

1 you.

2 MS. JOHNSON: All right. Let's see.
3 Ruth? Oh, sorry, Karl, was that a response to
4 Deborah's --

5 MEMBER STEINBERG: No, I was just, I
6 don't mean to be out of order, but I just want to
7 say it's been a real honor to be here with all
8 you guys, and I look forward to working with you
9 more. Thanks.

10 MS. JOHNSON: Thank you, Karl.

11 MEMBER LIND: Hi, this is Alice. Can
12 I just get in the queue?

13 MS. JOHNSON: Yes, why don't you go
14 ahead, Alice, and then we'll go to Ruth.

15 MEMBER LIND: Sorry, Ruth. So I just
16 have a couple of real quick thoughts. One is
17 just about triaging some of these measures by
18 particularly under-served populations. So one
19 would be getting better data and a measure about
20 people with serious mental illness and their
21 being offered and then their take-up use of
22 hospice and palliative care.

1 Another which is even more
2 problematic, I think is people with substance
3 abuse disorder history, and similarly, their
4 being offered and their take-up use of palliative
5 and hospice care. And so those are two that I
6 think we just need to measure, kind of
7 utilization measures.

8 Another kind of butter topic is
9 coverage for palliative care, especially with
10 private insurance and then also with Medicaid,
11 which varies from state to state. And it becomes
12 kind of problematic for people who are on both
13 Medicare and Medicaid at times to have those two
14 benefits coordinated, and so we trip across this
15 in Duals Committee from time to time, knowing
16 what the total cost of care is and whether people
17 are being referred appropriately if they have
18 both Medicare and Medicaid.

19 On a similar notion, most of the
20 really excellent demonstrations that go on in
21 Medicare right now or in Medicare/Medicaid
22 demonstrations exclude people on hospice,

1 precisely because the costs are kind of self-
2 contained, and so it's hard to see cost different
3 outcome when people are already on hospice at the
4 time that the demonstration starts. And so it's
5 something that needs to be looked at for
6 demonstrations just to raise the question, should
7 new demonstrations be offered through the
8 Innovation Center that target this population in
9 a specific way?

10 So I think those are my main thoughts,
11 and I thank you very much for letting me
12 participate by phone.

13 MS. JOHNSON: Thank you, Alice. Ruth?

14 MEMBER MACINTOSH: Thank you. Most of
15 my question was answered about the process, but
16 one thing I just want to have more clarity on is
17 yesterday, a lot of times we were bringing up
18 things about the specifications, and we learned
19 quickly, can't change them. But there was
20 recommendations, and who's going to be the voice
21 from here to where those need to go?

22 MS. JOHNSON: Just so you know, when

1 we go through and write the report, those kind of
2 comments come out, and we actually put those in
3 the gap discussion. So if you guys mentioned
4 yesterday, we need a measure here or if you would
5 change this measure this would help, that will
6 work its way to the gaps listing, as well.

7 MEMBER MACINTOSH: Thank you.

8 MS. JOHNSON: Michelle?

9 MEMBER CAUGHEY: Oh, thank you. I was
10 -- I have sort of this framework in my head, and
11 so I started to write it down. And I appreciate
12 other comments.

13 So you start out with a population of
14 patients who you want to serve in a palliative
15 sense or in a hospice sense, and I think Alice's
16 comments were right on. Are we actually serving
17 the patients who need that care, right? Do we
18 identify who needs it and who doesn't? So that's
19 sort of the population.

20 Then you think the ideal outcome
21 measure, in my mind, is have you then, having
22 identified patients who are in some kind of

1 distress, have you actually reduced that stress?
2 So that would be your outcome measure, right?
3 Measuring, you know, the level of distress before
4 you intervene versus after you intervene is
5 something actually we're going to attempt, but I
6 think it's not -- so in the current world, we're
7 sort of stuck either patient-reported outcomes of
8 distress, like how well in the HCAHPS, did you -
9 - they're very indirect, right? Or process
10 measures, right? Which we know, process measures
11 we hope move us along. They're not the end. We
12 need them now because we don't have measures
13 that, in whatever domain, that would be the true
14 outcome that we would be looking for in either an
15 individual or in a population of patients.

16 So sometimes we have sort of
17 intermediate outcomes. I'm not quite sure where
18 -- I mean, we've talked a little bit about that,
19 but I'm not sure exactly what that is. So,
20 anyway, that's sort of a framework that I'm
21 dealing with and I think might help improve the
22 conversation.

1 The population issue that Alice
2 brought up I think is really important because
3 there are patients who need this care who aren't
4 getting it, and they're in all these places
5 because the resources are so limited. So how we
6 actually decide who gets it, the algorithms
7 there, and how we then measure that, I don't
8 know. Anyway, just a thought.

9 MS. JOHNSON: Okay, thank you. I'm
10 looking at the clock. There's a couple of other
11 things that I desperately want to get to before
12 we go to public comment, so I'm going to let
13 everybody have a really quick word, if it's at
14 all possible. So Paul?

15 MEMBER TATUM: Very fast. I was
16 thinking about methodologies where you vote after
17 a big discussion like this, and I'd just say if I
18 only had one star, I'd hop onto Amy Berman's.
19 How we measure what palliative is is just so
20 critically important. If I got five stars, she
21 gets four, Arif gets one burnout. Just such
22 critical, critical issues for our field. Just to

1 kind of tease that back into this discussion. I
2 think those are really crisis issues for us.

3 MS. JOHNSON: Tracy, is yours still
4 up? Is that a new -- okay. Amy?

5 MEMBER SANDERS: So I just want to add
6 one more, and, Gregg, I'm going to respond to
7 what you said and also to, I guess, what Sean
8 said before he left. I'm going to look at this
9 with a serious illness frame, and let me also
10 state that the National Academy of Medicine, they
11 are using that terminology and that framing.
12 They're going to be doing a serious illness
13 roundtable, so that would be consistent with how
14 they're viewing.

15 But care concordance, treatment
16 concordant with people's values and preferences,
17 that is a challenging area. That's kind of the
18 center, and it's the area we kind of look away
19 from because it's just too hard to measure.

20 So I want to point out that Mary
21 Tinetti and Caroline Blaum are doing work called
22 Patient Priority Care, and it is work that is in

1 partnership with the Patient Centered Outcomes
2 Research Institute. They're working within a
3 large ACO across the state of Connecticut. They
4 are eliciting goals, and then they are working
5 with the major medical societies, the ACC, ACP,
6 ABIM, to then translate out what that actually
7 means. And so while that may seem to be kind of
8 not possible, it not only is possible, but there
9 are going to be measures developed out in this
10 area. So I would say that that is strongly an
11 area that we can go to looking in. And in the
12 interest of full disclosure, we're funding that.

13 The Society of Academic Emergency
14 Medicine, as we speak, is having their consensus
15 conference on just the topic that you're
16 suggesting, which is around how do we do shared
17 decision-making, advanced care planning in the
18 emergency room. That's where I came from before
19 coming here.

20 CMS, if they are on the line, the
21 question around primary and specialty palliative
22 care, this is an issue that only they can

1 address. How do we get access to that data means
2 that they need to change the way in which data is
3 reported so that they can note this. This is a
4 fundamental need of a large number of their
5 beneficiaries so that we can measure value. So
6 CMS, you can only address this, CMS, if you're
7 listening.

8 And the last is a gap just to add to
9 your list. Stage 4, one of the measures talked
10 about stage 4. We don't restage. NIH, National
11 Library of Medicine, any source you'll go to, we
12 don't restage. In other words, you can't look in
13 data, and looking at natural language is the
14 least feasible way of doing this. And so that
15 wasn't part of our discussion because that's not
16 our charge, but it really is a gap. And the
17 bigger issue is that we should always be looking
18 at pain. We don't have to wait until somebody is
19 stage 4.

20 So in terms of addressing these kinds
21 of measures, that's a fundamental flaw. It will
22 not be easy for anybody to look at or address

1 from a systems perspective, maybe from an
2 individual provider perspective. But we really
3 have to systematize to optimize the use and
4 usability, so I just share that.

5 MS. JOHNSON: Thank you. And then
6 I'll go over to Tracy.

7 MEMBER SCHROEPFER: So I just wanted
8 to put out there I think that I agree with Laura
9 about the issue of palliative care and the
10 confusion around that and that what I think would
11 be an interesting measure would be one that
12 really asked patients were they offered
13 palliative care. My brother has stage 4 lung
14 cancer, and his oncologist, I told him to ask him
15 about palliative care, and the oncologist, he
16 said, "No, we don't do palliative care. You're
17 not hospice yet," and so I told my brother to go
18 back and here's the definition, and he did. And
19 so now he's getting palliative care.

20 And then the other thing is the
21 insurance piece of that and insurance companies.
22 Just because the other thing, he's been waiting

1 three weeks for approval for chemo for
2 palliation. So I think there is a lot of issues
3 around that.

4 MS. JOHNSON: Thank you. Linda?

5 MEMBER SCHWIMMER: I had a comment on
6 the reference to ethical and legal in the
7 document, and I think this relates to what we
8 were talking about yesterday where we were
9 talking about the post forums and advanced care
10 directive and lack of clarity or enough
11 information or legally-binding information, and
12 so we're measuring all these things, and we have
13 this different terminology in some of these
14 measures, but will it actually even make a
15 difference? And we're here to make a difference.

16 And so I think that there's a way for
17 us to do that in terms of working with the legal
18 community, with surrogates, and to maybe --
19 looking at documents, whether that's documents
20 that become part of this process or whether --
21 I'm not exactly sure, but I do think that's
22 something that we should look at. I know it's

1 state by state, and I know that there are some
2 models, though, that are accepted across state
3 lines. And to think about that, to then ensure
4 that all this work, in terms of asking if they
5 have an advanced directive or making sure that
6 it's in the chart or in the electronic records,
7 et cetera, it all kind of falls apart when you
8 get to the legal aspect of it, which seems like
9 such a waste, right?

10 So, you know, I'd love to be able to
11 figure out how to do that as the only lawyer on
12 the Committee. So thank you.

13 MS. JOHNSON: All right. Last word,
14 Arif.

15 MEMBER KAMAL: So I'd like to put my
16 full enthusiasm and energy behind the idea of a
17 white paper manuscript, something that sort of
18 carries forward for the field because all of us,
19 I think, individually could write a letter to the
20 editor, and some of us have, in fact, done that
21 kind of thing. But that single voice only
22 carries so much. I think the voice of this group

1 would be really important.

2 I additionally reflect on the fact --
3 so my brother is an orthopedic surgeon, and so
4 the quality of his care is evaluated by how he
5 cuts, okay? And when I wear my oncologist hat,
6 the procedure that I perform would be to provide
7 chemotherapy in a very superficial, I'm wearing
8 my, you know, oncologist hat only, way. And so
9 most of the quality measures that are in oncology
10 have to do with timeliness and appropriateness of
11 the chemotherapy that I perform.

12 In the field that we're in, when my
13 brother asked me so what is it that you actually
14 do, I say we communicate with people. And so he,
15 being a quality person, said, so where are all
16 the quality measures about evaluating how often
17 and how well you communicate with people? And I
18 looked and said uh --- right? And he said,
19 "Well, you would evaluate us on how we cut,
20 right?" And so we should be evaluated on how we
21 have family meetings, do prognostic disclosures,
22 share information. All these things are very

1 unstandardized, right? How many of us in the
2 room have received formalized feedback on
3 conducting a family meeting, right? Especially
4 if you didn't do a fellowship where maybe it was
5 required but, otherwise, sort of how often do we
6 receive that feedback? How often do we receive
7 that feedback from patients outside of HCAHPS
8 scores where we might get that as individuals, et
9 cetera. So I think we should re-evaluate what we
10 do as our procedure and then how are we
11 evaluating from a quality measure perspective.

12 MS. JOHNSON: Very interesting. And,
13 actually, I'm really looking at time here. Let's
14 go to the next slide about our off-cycle because
15 a couple of you I think talked about this a
16 little bit and have given some ideas already, the
17 white paper idea for example, maybe even Linda's
18 ethical legal looks.

19 We will be doing off-cycle activities.
20 What does that mean? That means we're going to
21 finish up this endorsement process. We've got
22 another four or five months, six months,

1 something like that, Rachel would know better, to
2 finish this process up. But then after that,
3 we're going to gather you guys together quarterly
4 after that to do some other work, and this is
5 just some ideas on what some of this other work
6 might be. It could be pulling you guys together
7 to help other committees think about something.
8 If something comes along, it's in your
9 wheelhouse, but maybe another group is looking at
10 it. You guys could help.

11 And I'm going to read this whole
12 thing. Ad hoc reviews if something comes in that
13 we need another endorsement look. Educational
14 activities either to our membership or to other
15 committees, et cetera. So there's lots of things
16 that we could potentially do.

17 I don't -- we don't have time,
18 actually, unfortunately, to start our brains
19 going on that. What we do have, and I just want
20 to get your feeling on this, and whichever way it
21 goes is fine. We have a meeting scheduled by
22 phone in about a week or so. It should be on

1 your calendars. Thank you. I'm stealing
2 Rachel's thunder a little bit here. That call
3 was set up really to get some time on your
4 calendars. You guys are busy. We wanted to get
5 that time on your calendar for the idea that if
6 we didn't finish our work today, we would have
7 that call, and we could finish up a measure
8 evaluation if we needed to.

9 Do you have any appetite for
10 continuing this discussion and potential ideas
11 for off-cycle work on a call next week? That's
12 one option. It's already on your calendar. Or
13 would you rather wait, we'll do some back and
14 forth and maybe some polling through email or
15 other ways, when we get a little bit closer to
16 our first-quarter off-cycle work?

17 So do you care one way or the other?
18 I don't want to use your time if you don't think
19 it's worth it on this call next week.

20 MEMBER HANDZO: I vote for an email
21 poll.

22 MS. JOHNSON: Okay. So we got two

1 emails. Is that okay with everybody? Okay.
2 We'll do that on email. I can't think of any
3 reason that we would need to have that call.
4 It's the post-meeting call, May 20th. Am I
5 missing something? Is anybody -- no, we don't
6 have to vote on that. All right. Yes? That's
7 the August 3rd. All the consensus not reached
8 stuff that happened -- so apologies. This post-
9 meeting call is kind of new, and, again, we put
10 it on your calendars just in case we don't finish
11 something today. If we had 30 measures, and we
12 just couldn't get through all of them, we would
13 have this call.

14 We will -- again, sorry, Rachel,
15 stealing your thunder here a little bit. We will
16 write up our report, and we put that out for a
17 30-day public and member comment period. When
18 those comments come through, we as staff will
19 take those comments and gather them together. We
20 will provide draft responses from you guys, and
21 then we'll get you on the phone, and we're going
22 to talk about those comments. And some of those

1 comments may very well make you want to
2 reconsider some of the decisions that were made
3 today, and, if that's so, that's fine because
4 that's part of what the comment period is for.
5 And at that point, the consensus not reached
6 measures will also be readdressed. So, again,
7 that's in August. Found time, yes. You guys
8 just found two hours, yes.

9 Now, I know we still have to do public
10 comment and next steps. I want to take about
11 four minutes, according to that clock, and get a
12 little bit of feedback from you guys on our
13 process. And I'm particularly interested, if you
14 think it's great, we love that kind of
15 interesting feedback, but maybe what do we need
16 to do better? And specifically we have this new
17 maintenance process that you guys are seeing.
18 You're some of the first ones to have seen this.
19 How is that working for you? The preliminary
20 analysis that we as staff did, how did that work?
21 The ratings that we did as part of the
22 preliminary analysis, was that useful or not?

1 Anything else is on the table, as
2 well. I realize I've given you three minutes,
3 but if there's anything that you really think we
4 need to work on, we'd like to hear. And Amy?

5 MEMBER BERMAN: I thought the process
6 was exceptional. The staff was exceptional, as
7 well. In the PDFing of the document, it wasn't
8 in numerical order throughout, so that made it a
9 little harder when we wanted to go and turn to --
10 it should either be in the order of the agenda or
11 in numerical order so that it's easy for us to
12 find in the PDFed version.

13 MS. JOHNSON: Okay. And we'll get
14 with you. I'm not exactly sure which PDF, so
15 I'll talk to you offline to make sure I
16 understand that one. Okay. George?

17 MEMBER HANDZO: Two things. I think
18 the orientation for me was extremely helpful. I
19 would have, in addition, in retrospect,
20 benefitted from more of an opportunity to run
21 through a case example and actually discuss it,
22 you know, not just read here's a good one but

1 what we were looking at what did we get; what are
2 the questions, and that would have just made my
3 life much easier.

4 I had -- I don't know if anybody else,
5 but the hyperlinks from the staff document to the
6 regular document, I got there, but then I had to
7 scroll back.

8 MS. JOHNSON: Oh, you couldn't get
9 back?

10 MEMBER HANDZO: I couldn't get back.

11 MS. JOHNSON: You're a Mac user?

12 MEMBER HANDZO: Yes.

13 MS. JOHNSON: Yes, there's a special
14 command for Mac users. So we are going to add
15 that but --

16 MEMBER HANDZO: Guess what? Mac is
17 taking over the world. Get used to it. Mac
18 users need some love here.

19 MS. JOHNSON: Okay, great. Thank you.
20 Deborah?

21 CHAIR WALDROP: I just can't say
22 enough in terms of thanks to the staff for the

1 measure evaluation worksheets. They were really
2 terrific. Thank you for that and for all of your
3 responsiveness and help with questions.

4 MS. JOHNSON: Amy?

5 MEMBER SANDERS: I thought the
6 algorithms were particularly helpful, especially
7 as sort of a first-time NQF participant. And the
8 one thing that would have been helpful for me,
9 but this may not be universal, because of the
10 nature of my work, it was a touch-and-go kind of
11 thing about whether or not I was going to be able
12 to have the time to commit, not in general but
13 because I'm planned out fairly far in advance.
14 And this was all really sort of set up less than
15 two months from the time of the actual meetings,
16 and, for me, more lead time would have been
17 helpful. But that probably, for the overall NQF
18 process, I can see where that would be also
19 problematic, and maybe dealing with squeaky
20 wheels like me is easier on an ad hoc basis than
21 reconfiguring the entire world.

22 MS. JOHNSON: Thank you. Appreciate

1 it. Laura?

2 MEMBER PORTER: I think it would have
3 been helpful to get all of the comments from the
4 workgroup call. Don't tell me we had them
5 posted. Oh, good, okay. I've missed enough
6 things today.

7 MS. JOHNSON: A workgroup summary, is
8 that what you mean?

9 MEMBER PORTER: So a workgroup
10 summary. Yes, I think that would be helpful.

11 MS. JOHNSON: We actually did, just so
12 you know, we did used to do that. When we
13 instituted those preliminary analysis, those take
14 our staff so long that we ended up having to push
15 our time line, but we can only push so much. So
16 one of the things that we said is we will take
17 out those workgroup summaries.

18 So, you know, nothing is ever written
19 in stone here. They could come back. But we
20 appreciate the feedback. Tracy?

21 MEMBER SCHROEPFER: So I did the 2012
22 when we did that, and I just want to say I

1 thought this was great. I thought everything --
2 you all made so many improvements and changes.
3 And in particular, the only thing I can say for
4 the two is that it always seems like we're so
5 short of time by doing it just for a day and
6 usually it's not quite a half. Sometimes I think
7 maybe linking it to two full days and then the
8 half might be helpful because I think sometimes
9 people do want to say more, and they feel rushed.
10 So that's one thing, and it would have been neat
11 to be able to do some of this today.

12 And then the other thing is the
13 dinner. I thought the dinner was really great
14 because it gave us a chance to get to know each
15 other a little bit, particularly since we'll be a
16 standing committee, and maybe just getting that
17 information ahead of time because some people
18 couldn't come because they had already made
19 plans. But that was great.

20 MS. JOHNSON: Okay. Great, thank you.
21 And, Doug, last word on this?

22 MEMBER NEE: Sure. I'd like to echo

1 what Tracy just said. Having been at the
2 previous one, this is light years better than it
3 was before, for perspective for those of you who
4 weren't. Yes, everything went wonderfully well.

5 I think the workgroup sessions were
6 helpful. There was a certain dynamic difference
7 between the workgroup session on the phone and
8 what we actually do here. If it's at all
9 possible, and I emphasize that, if you had
10 recordings of a session where we went from A to Z
11 through a process and a measure, we went through
12 a measure, that someone who hadn't been on this
13 committee before could actually listen to, not
14 the shortcutting we got into, you know, later on
15 in the afternoon and today but, I mean, just a
16 full-on, you know, here's how we went through
17 everything, what the call was, what the responses
18 were, and how the information was provided by
19 those that were leading the discussion I think
20 would be extremely helpful to those who haven't
21 ever been on this before. And it may very well
22 help them put all of the written material that

1 they have in front of them that they're trying to
2 desperately digest into some sort of verbiage
3 that makes sense and is not embarrassing when
4 they get to the meeting here.

5 MS. JOHNSON: Great suggestion. Thank
6 you. That's actually a pretty easily doable one.
7 And, Amy, something burning?

8 MEMBER SANDERS: Burning a little bit,
9 yes. Thank you. So one way that you might be
10 able to eat your cake and have it, too, with
11 regard to a post-working group pre-meeting
12 summary would be to task the primary respondent
13 for a given measure with writing up a summary,
14 which I think would provide a summary for other
15 people and would also help the primary discussant
16 to be prepared in a smooth fashion. So speaking
17 only for my own presentation yesterday, that
18 could have gone a little bit more smoothly I
19 thought, and perhaps if I had that kind of extra
20 step, I would have made a better presentation.
21 So just a --

22 MS. JOHNSON: Very interesting. As

1 staff, I'm like, oh, wow, give it to somebody
2 else. That's an interesting idea. Thank you so
3 much. With that, let's go to public comment,
4 Rachel, and then tell us our last steps.

5 MS. ROILAND: Operator, if you could
6 open the lines for public comment, that would be
7 great. Thank you.

8 OPERATOR: Okay. At this time, if you
9 would like to make a comment, please press star
10 and then the number 1. There are no public
11 comments at this time.

12 MS. ROILAND: All right. Are there
13 any public comments in the room? All right. So
14 there are no public comments. And I'm actually
15 going to turn it over to Jean-Luc to close us
16 out.

17 MR. TILLY: That's right. So we
18 talked a little bit about the post-meeting call,
19 which we won't be having, so strike that. We'll
20 post the draft report for public member comment a
21 little bit later in June and give you a couple of
22 months to think about that and write about it.

1 We'll reconvene on August 3rd to write up our
2 comments and our responses.

3 Again, the report will be posted for
4 a little bit of a shorter period, just two weeks,
5 for NQF members to vote and the CSAC, or the
6 Consensus Standards Advisory Committee, will get
7 a chance to look at it and approve it, as well as
8 our board and take the next step with that.

9 Then we'll have a little month period
10 for appeals, and unless there are any or
11 depending on how those are adjudicated, we'll
12 close out at around November or early December.
13 That's pretty much all there is unless you have
14 any questions.

15 MEMBER RITCHIE: Do you have any idea
16 about what the schedule is for next year?

17 MS. JOHNSON: No, we haven't, but we
18 would probably be smart to try to think on your
19 calendar sooner, rather than later. That's
20 actually a really good idea, so let me see what
21 we can do with that and try to do that.

22 MEMBER TATUM: So for my clinic, they

1 like six months' notice to --

2 MS. JOHNSON: Six months. Okay. We
3 might could do six months. We might could do six
4 months if we start now, yes.

5 This has been lovely. Thank you so
6 much. I know this is hard work. I know there's
7 a lot of nuances. I know you're volunteers and
8 you actually have another life outside of our
9 world, but we appreciate it very much. I've
10 really enjoyed getting to talk to you guys and
11 know you guys a little bit better.

12 So thank you. Safe travels.

13 (Whereupon, the above-entitled matter
14 went off the record at 2:01 p.m.)

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C E R T I F I C A T E

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
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