

NATIONAL QUALITY FORUM

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PALLIATIVE AND END-OF-LIFE CARE  
STEERING COMMITTEE MEETING

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TUESDAY,  
MAY 10, 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 8:30 a.m., R. Sean Morrison and Deborah Waldrop, Co-Chairs, presiding.

PRESENT:

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

MICHELLE CAUGHEY, MD, FACP, Associate Executive  
Director, The Permanente Medical Group,  
Kaiser Permanente

GEORGE HANDZO, BCC, CSSBB, Director, Health  
Services Research and Quality, HealthCare  
Chaplaincy

ARIF H. KAMAL, MD, MHS, FACP, FAAHPM, Physician  
Quality and Outcomes Officer, Duke Cancer  
Institute

ALICE LIND, MPH, BSN, Manager, Grants and Program  
Development, Health Care Authority\*

RUTH MacINTOSH, RN, Continuum of Care Manager,  
Aetna

ALVIN MOSS, MD, FACP, FAAHPM, Director, Center  
for Health Ethics and Law; Professor of  
Medicine, Robert C. Byrd Health Sciences  
Center of West Virginia University

DOUGLAS NEE, Pharm D., MS, Clinical Pharmacist

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

CINDI PURSLEY, RN, CHPN, Administrator, VNA  
Colorado Hospice and Palliative Care

AMY SANDERS, MD, MS, FAAN, Assistant Professor,  
Director of Cognitive and Behavioral  
Neurology, Departmental Quality Officer\*

TRACY SCHROEPFER, PhD, MSW, Associate Professor  
of Social Work, University of Wisconsin,  
Madison, School of Social Work

LINDA SCHWIMMER, Attorney, Vice President, NJ  
Health Care Quality Institute

CHRISTINE SEEL RITCHIE, MD, MSPH, Professor of  
Medicine in Residence, Harris Fishbon  
Distinguished Professor for Clinical  
Translational Research in Aging, University  
of California San Francisco; Jewish Home of  
  
San Francisco Center for Research on Aging

ROBERT SIDLOW, MD, MBA, FACP, Division Head,  
  
Survivorship and Supportive Care, Memorial  
  
Sloan Kettering Cancer Center

KARL STEINBERG, MD, CMD, Medical Director,  
Kindred Village Square Transitional Care and  
Rehabilitation Center; Life Care Center of  
Vista; Carlsbad by the Sea Care Center;  
Hospice by the Sea

PAUL E. TATUM, MD, MSPH, CMD, FAAHPM, AGSF,  
Associate Professor of Clinical Family and  
Community Medicine, University of  
Missouri-Columbia School of Medicine

GREGG VANDEKIEFT, MD, MA, Medical Director for  
Palliative Care, Providence Health &  
Services

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

#### NQF STAFF:

ANN HAMMERSMITH, JD, General Counsel

KAREN JOHNSON, MS, Senior Director

ELISA MUNTHALI, MPH, Vice President, Quality  
Measurement

RACHEL ROILAND, Senior Project Manager

JEAN-LUC TILLY, Project Analyst

MARCIA WILSON, PhD, MBA, Senior Vice President,  
Quality Measurement

#### ALSO PRESENT:

KATHERINE AST, AAHPM

LAURA HANSON, UNC Chapel Hill

KARL LORENZ, RAND Corporation\*

STACIE SINCLAIR, Center to Advance Palliative  
Care

CARL SCHEFFEY, NHPCO

CAROL SPENCE, NHPCO

NEIL WENGER, UCLA Health\*

\* present by teleconference

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

8:36 a.m.

MS. ROILAND: Good morning, everyone,  
if we could just take our seats, and we'll get  
started.

MEMBER ARCHULETA: All right. Yes,  
hi, Bob Archuleta.

MS. ROILAND: Hi, Bob. Welcome.

MEMBER ARCHULETA: Thank you.

MS. ROILAND: Alice, are you also on  
the phone?

MEMBER ARCHULETA: Yes.

MEMBER LIND: Yes, I am.

MS. ROILAND: I'm sorry, who is that?

MEMBER LIND: Yes, this is Alice. I'm  
on.

MS. ROILAND: Oh, all right. Thank  
you, Alice. All right. Welcome, everybody, and  
thank you for coming and traveling all this way  
to Washington, DC, today for our Palliative and  
End-of-Life Care Committee Meeting.

So, and a lot of you have spoken with

1 me on the phone or through email or with lots of  
2 people on the project team, so I'm very excited  
3 to meet you all in person, so thank you.

4 So like I said, my name's Rachel  
5 Roiland and I'm a senior project manager here at  
6 NQF, and I'm just sort of going to kick us off  
7 today, and so I wanted to start with a few  
8 housekeeping things.

9 What you'll see on the -- in your  
10 microphones in front of you we have a bunch of  
11 handouts that we put out on your desk this  
12 morning, and within those handouts we have the  
13 agenda for today's meeting and within that agenda  
14 you'll see just sort of the order of measures  
15 that we'll be reviewing today.

16 In addition to the agenda, we have  
17 printed out the algorithms that we use for  
18 several of our evaluation criteria, so if you  
19 have any questions about how we arrive at  
20 whatever decision we end up arriving at, we will  
21 be guided by these algorithms. So if you have  
22 any questions please refer to those.

1                   And also the last sheet of paper that  
2 we have for you is just the recusal sheet that  
3 lists out who might need to be recused for a  
4 given measure given that they've worked on it in  
5 some capacity in the past. We try to be as open  
6 and clear about this as possible, so that's why  
7 we have this sheet.

8                   And so a couple of other housekeeping  
9 things, we just have the restrooms located just  
10 near the elevators that you got off of. If you  
11 just take a right after those elevators that's  
12 where the restrooms are located.

13                   We do try to be kind and incorporate  
14 some breaks into our schedule, and so we have  
15 three of those scheduled for today. One is at,  
16 our first one is a 15-minute break at 10:30, and  
17 then we have lunch at about 11 -- 12:45, I'm  
18 sorry -- teased you there. And then that will be  
19 provided here at NQF and we'll have about a half  
20 an hour for lunch, and then we'll have an  
21 afternoon break of about 15 minutes around 3:00.

22                   We do have reservations for tonight



1 for dinner at 5:45, so a true Midwestern time for  
2 dinner for lots of you East Coasters who like to  
3 eat at 9:00m but it's very close. It's about a  
4 block and a half or two blocks away at P.J.  
5 Clarke's, so we have a reservation for 23 so we'd  
6 be happy for all of you to join us over there,  
7 and we'll be walking over there together at the  
8 end of the day.

9 Just some sort of connectivity issues  
10 for those of you with laptops or cell phones that  
11 have Wi-Fi access, the username and password is  
12 listed up there for the Wi-Fi network.

13 And we do know that you are all busy  
14 folks with lives outside of this room and  
15 probably have your cell phones with you, and we  
16 just ask that you mute those during the meeting  
17 because they can just be a bit disruptive if they  
18 go off when we're doing discussion or voting.

19 And with that -- oh, a few other  
20 housekeeping things. These microphones, you  
21 really need to get up close to them in order for  
22 everyone on the phone to hear you as well as

1 everyone in the back of the room. So please make  
2 sure you speak directly into the microphone.

3 Also, only about two to three of these  
4 -- three of them can be on at the same time. So  
5 if we have more than that the other ones won't  
6 work. And when you get into discussion you'll  
7 see how easy it is to forget to turn your mic off  
8 when you're done speaking, so just try to be  
9 cognizant of that.

10 And the last bit of housekeeping is  
11 that we have the name tents that we ask if you  
12 just could sort of angle them towards us so we  
13 can better see who's who that would be really  
14 helpful. And then when you want to speak I just  
15 would like for you to sort of tilt your name tag  
16 up like this, so it signals to us that you want  
17 to speak and it'll help the co-chairs just  
18 facilitate the discussion a little bit better.

19 And if you just want to go to the next  
20 slide, Jean-Luc. And then just -- I should have  
21 done this in the beginning, I'm sorry, but just  
22 to sort of introduce all the staff here today

1 that's here to help you and just guide you  
2 through this process.

3 Again I'm Rachel Roiland. I have  
4 Jean-Luc Tilly at -- to my right. He's the  
5 project analyst and he's the voting guru. So he  
6 will guide us through the lovely voting process  
7 that we have set up for you today.

8 Down at the far end of the table we  
9 have Marcia, Marcia Wilson, excuse me, a senior  
10 vice president here in the Quality Measurement  
11 Department at NQF, so she is our quality  
12 measurement guru, as well as we have Karen  
13 Johnson our senior director for this project as  
14 well sitting right next to Marcia.

15 And she is the one who has led us  
16 through all our workgroup calls and will be our  
17 methods guru for today as well. And then over  
18 here to my right at the side table is Elisa  
19 Munthali, another vice president here in Quality  
20 Measurement.

21 So, all right. And so with that I  
22 will turn it over to our co-chairs to do their

1 own introductions.

2 CHAIR MORRISON: So good morning,  
3 everybody, and welcome to NQF. This is, I think,  
4 for all of us a very exciting time as a field.  
5 Palliative care has evolved to the point where  
6 NQF now has a standing committee on measures and  
7 this is the second time that this committee has  
8 actually met. In the past, I guess it was five  
9 years ago, Karen, or more, this was a temporary  
10 committee, so kudos to NQF and thank you for  
11 doing that.

12 My name is Sean Morrison. I am from  
13 the Mount Sinai School of Medicine in New York  
14 City, and my partner in crime here, Deborah  
15 Waldrop, and I will be co-chairing today's  
16 session and tomorrow.

17 And for those of you who have not been  
18 on an NQF panel, and I have, let me just run  
19 through a couple of helpful hints for the next  
20 two days before I have Deb introduce herself. Is  
21 that right? Okay.

22 So our role, quite honestly, is to

1 make sure things move smoothly and relatively  
2 quickly. We will be here until we get through  
3 the agenda for today and tomorrow, so that  
4 whether we finish early or whether we finish on  
5 Thursday morning in the wee hours really depends  
6 upon all of you. It is -- we can't stop and we  
7 will break today at our regular time, but how  
8 late we go tomorrow really depends on the work of  
9 this group.

10 So a couple of perhaps helpful hints,  
11 we will ask the lead discussant to walk us  
12 through the various components of the measures  
13 and each of the measures has two or three  
14 additional discussants.

15 It is not necessary to repeat  
16 everything that the lead discussant said if you  
17 agree with it. You can simply say concur or  
18 point out areas of differences.

19 Similarly, we are going to have, I  
20 suspect, a lot of discussion around the various  
21 measures, and believe it or not those discussions  
22 can get and feel very personal. It feels very

1 strange to be looking at a series of quality  
2 metrics and have a very strong emotional  
3 attachment to them. Believe me, it happens.

4 So what I would ask and what we would  
5 really hope is the following. This is not really  
6 a debate where you're attempting to convince the  
7 other side about the goodness of your heart and  
8 the goodness of the measure, so this is an  
9 opportunity for all of us to weigh the various  
10 aspects of each individual measure.

11 If somebody articulates a point, feel  
12 free not to raise your tent card and say I agree  
13 with this person and I particularly want to  
14 highlight how important that point is and how  
15 strongly I feel about it -- not necessary.

16 If you have an additional area of  
17 concern please raise it. If you have an  
18 additional area of strength feel free to raise  
19 it, but Deborah and I are going to try really  
20 hard to keep comments really focused and novel  
21 rather than repetitive this is really what I  
22 believe.

1 Trust me, if we go the former route we  
2 will be here for a very, very long time. And  
3 please, please don't take it personally if either  
4 of us interrupt and say that's a great point but  
5 I think we need to move on. Does that work for  
6 people?

7 The last thing, Rachel was very nice  
8 about it, we are all incredibly busy people.  
9 Everybody in this room will be multitasking. I  
10 understand that. Deborah understands that.  
11 Karen understands that. Rachel understands that.

12 That being said, we do have 15-minute  
13 break schedules which are either for the bathroom  
14 or for emails that don't have to be answered  
15 right away.

16 So I guess what we would ask is if you  
17 take a look at your email, you take a look at  
18 your texts, and there's something that really can  
19 wait until the break, we'd love it if you could  
20 just pile those up and answer them at that time,  
21 or even better at lunch. If people are focused  
22 the discussions tend to go a lot faster and

1 smoother.

2 And the last part is, I suspect a lot  
3 of you here around the room, including me, are  
4 thinking about what is this day going to be like  
5 and what am I supposed to be doing. Yes, I have  
6 absolutely no idea either. That's why Rachel and  
7 Karen are on either side of us.

8 And they will weigh in when we get  
9 lost and they are both close enough that they can  
10 step on both Deborah and my toes simultaneously  
11 if things are not going smoothly. So relax, it's  
12 going to be a lot of fun.

13 Deborah.

14 CHAIR WALDROP: It's really an honor  
15 and a privilege to be here in this room among all  
16 of you with all the expertise that's surrounding  
17 us. Thank you for your shared commitment to  
18 making the end-of-life care that we provide in  
19 this country better.

20 I also want to say thank you to the  
21 staff. You've been incredibly responsive. I  
22 know to me as a new person in this process and



1       probably to those of you who are also new around  
2       the table, they answer emails immediately  
3       quickly, or amazingly quickly, and have provided  
4       us with great information that helps, really, I  
5       think, smooth this process out.

6               So I too will be depending on them to  
7       help us know exactly how to keep you and all of  
8       us on track. So thank you for being here. I  
9       look forward to the next two days and all that  
10      we're going to be able to accomplish together,  
11      and I think I turn it over to Ann.

12             MS. HAMMERSMITH: Thank you. Good  
13      morning, everyone. I'm Ann Hammersmith. I'm  
14      NQF's general counsel, and I'm going to lead you  
15      through the disclosures of interest.

16             If you recall, we sent you a form in  
17      which we asked you detailed information about  
18      your professional activities. What we're going  
19      to do today, and those of you who have been on  
20      the committee previously have done this before,  
21      is we are going to go around the table and have  
22      you orally disclose any interests that you have

1 that are relevant to the work before the  
2 committee.

3 Just because you disclose does not  
4 mean that you have a conflict of interest. Part  
5 of the reason we do this is so that we are open  
6 and transparent about the activities of our  
7 committee members, open to the public, so that  
8 the public is aware of where you are coming from.

9 So what we are looking for you to  
10 disclose is if you have any activities that are  
11 relevant to the subject matter before the  
12 committee, only if relevant to the subject matter  
13 before the committee. We're especially  
14 interested in your disclosure of relevant  
15 speaking engagements, consulting, research,  
16 grants. Again, just because you disclose does  
17 not mean that you have a conflict of interest.

18 I also want to remind you that you sit  
19 on the committee as an individual. You don't  
20 represent your employer's interests, you don't  
21 represent the interests of anyone who may have  
22 nominated you to serve on this committee. You're

1 here as an individual expert.

2 So with that I'll ask you to go around  
3 the table, tell us who you are, who you're with,  
4 and if you have anything you would like to  
5 disclose. And I'll start with the co-chairs.

6 CHAIR WALDROP: I'm Deborah Waldrop  
7 from the University of Buffalo School of Social  
8 Work, and I have no disclosures to make.

9 CHAIR MORRISON: Sean Morrison from  
10 the Mount Sinai School of Medicine. Over a  
11 decade ago I sat on the technical advisory panel  
12 for the PEACE measures. It was so long ago that  
13 I don't remember it, but Rachel pointed it out to  
14 me. Otherwise I have nothing else to disclose.

15 MEMBER CASS: Thank you. I am Cleanne  
16 Cass. I am a hospice and palliative care  
17 physician. I've been doing this quite a while.  
18 I'm currently with Ohio's Hospice as their  
19 director for home care services. So we take care  
20 of about 300 patients a day at home, about a  
21 thousand on our census, and what I do is go out  
22 and see them in their homes.

1 I'm also the chair for the palliative  
2 care committee at the American Osteopathic  
3 Association, so I do some research allocation  
4 funding. Would probably be the only area I can  
5 think of that I would have a definite -- a direct  
6 kind of possible -- I don't think it's a conflict  
7 by any means but we do develop research projects.  
8 So thank you.

9 MEMBER WIEGAND: Great. Good morning, I'm  
10 Debra Wiegand. I teach at the University of  
11 Maryland School of Nursing, and I practice at  
12 Thomas Jefferson University Hospital in  
13 Philadelphia. I'm on the board of directors for  
14 HPNA, the nursing organization, and I have no  
15 conflicts.

16 MEMBER CAUGHEY: I'm Michelle Caughey.  
17 I'm a physician and work in northern California,  
18 Kaiser Permanente. I oversee the hospice and  
19 palliative care programs as well as hospital  
20 operations and some other things, ethics. I have  
21 no research or other conflicts.

22 MEMBER ATKINSON: Good morning. I'm

1 Margie Atkinson. I am the director for Pastoral  
2 Care, Ethics and Palliative Care for Morton Plant  
3 Mease Health Care, part of BayCare Health System  
4 in the Tampa Bay, Florida area.

5 I also serve on the National Coalition  
6 for Hospice and Palliative Care as president of  
7 the Association of Professional Chaplains, and I  
8 have nothing to disclose.

9 MEMBER NEE: Good morning. My name's  
10 Douglas Nee. I'm an independent consultant  
11 pharmacist out of San Diego. I have nothing to  
12 disclose.

13 MEMBER HANDZO: I'm George Handzo.  
14 I'm the director of health services, research,  
15 and quality at the HealthCare Chaplaincy Network.  
16 I'm a little jet lagged because I actually live  
17 in L.A.

18 And part of my job is to advocate for  
19 quality measures and quality indicators in  
20 spiritual care and chaplaincy care, but I have no  
21 particular involvement or interest in any  
22 measures before this group.

1                   MEMBER SIDLOW: My name is Rob Sidlow.  
2 I'm the head of Survivorship and Supportive Care  
3 at Memorial Sloan-Kettering. I do some part time  
4 consultancy work for a national for-profit  
5 hospice around their educational content, aside  
6 from that no conflicts.

7                   MEMBER KAMAL: Good morning, I'm Arif  
8 Kamal. I'm a medical oncologist and palliative  
9 care physician at Duke University.

10                   Regarding disclosures, I'm the  
11 incoming chair of the quality care committee for  
12 ASCO and on the palliative care measures panel  
13 task force, both of which are positions I've  
14 taken since the measures were submitted for  
15 maintenance.

16                   Additionally, I have an AHRQ K grant  
17 looking at benchmarks and performance for  
18 existing palliative care quality measures which  
19 are limited to the NQF-endorsed set from prior.

20                   MEMBER PORTER: Hi, I am Laura Porter  
21 and I'm a physician and a Stage 4 colon cancer  
22 survivor. And I'm with the Colon Cancer

1 Alliance. I have nothing to disclose.

2 MEMBER MACINTOSH: Good morning. I'm  
3 Ruth MacIntosh. My background is nurse. I'm a  
4 continuum of care manager for Aetna's palliative  
5 and end-of-life program. I have nothing to  
6 disclose.

7 MEMBER PURSLEY: Cindi Pursley. I'm  
8 the administrator of the Colorado Visiting Nurse  
9 Hospice and Palliative Care, and I have nothing  
10 to disclose.

11 MEMBER SCHROEPFER: Tracy Schroepfer,  
12 I'm a professor at the University of Wisconsin-  
13 Madison School of Social Work, and I have nothing  
14 to disclose.

15 MEMBER RITCHIE: Good morning.  
16 Christine Ritchie, I'm at the University of  
17 California San Francisco where I'm the professor  
18 of medicine there. And I'm the past president of  
19 the American Academy of Hospice and Palliative  
20 Medicine and currently chair the quality  
21 committee.

22 And my major point of disclosure,

1 which is actually listed separately, is I served  
2 on the advisory group for advanced illness  
3 initiative for California's 2020 MediCal  
4 demonstration waiver. And we chose a couple of  
5 the measures that actually are currently being  
6 discussed, and so I'll recuse myself from that.

7 MEMBER TATUM: Paul Tatum, University  
8 of Missouri. I'm a geriatrician with the  
9 American Geriatrics Society and a palliative  
10 medicine physician.

11 I don't believe I have any direct  
12 conflicts that would influence measures. I put a  
13 number of disclosures including that I sit on the  
14 board of the American Academy of Hospice and  
15 Palliative Medicine and the Hospice Medical  
16 Director Advisory Council for Hospice Compassus'  
17 now known as Compassus Hospice and Palliative  
18 Care.

19 MEMBER VANDEKIEFT: Hello, I'm Gregg  
20 VandeKieft. I'm a medical director for  
21 palliative care for Providence Health and  
22 Services, a five-state system on the West Coast,



1 and also serve as the advocacy and awareness  
2 strategic coordinating committee chair for the  
3 American Academy of Hospice and Palliative  
4 Medicine, practice both inpatient and outpatient  
5 palliative medicine.

6 I come from a family medicine  
7 background. I have no relevant disclosures.

8 MEMBER STEINBERG: I am Karl  
9 Steinberg. I just had cataract surgery a few  
10 days ago. I don't usually wear this kind of  
11 stuff. I know I'm too young, thank you. You  
12 don't have to say it. All right.

13 So I'm also outside of San Diego,  
14 originally a family physician. I'm kind of a  
15 long-term care geriatrician now, SNFologist I  
16 like to say because I feel SNFist lacks gravity.  
17 But I'm also a hospice medical director for a  
18 small for-profit hospice in San Diego.

19 As far as disclosures, I chair the  
20 Coalition for Compassionate Care of California.  
21 I don't get any pay from them, but they do have  
22 an advanced care planning consulting service. So

1 I don't know that that would be relevant, but  
2 just to put it out there.

3 MEMBER MOSS: Hi, I'm Woody Moss. I'm  
4 a professor of medicine at West Virginia  
5 University School of Medicine. I'm a  
6 nephrologist and a palliative care physician.

7 I chair the Coalition for Supportive  
8 Care of Kidney Patients, and I also have funding  
9 from the state of West Virginia to direct the  
10 West Virginia Center for End-of-Life Care.

11 MS. HAMMERSMITH: Okay, thank you. I  
12 understand that there's some committee members on  
13 the phone, so I'll call your names.

14 Amy Sanders. Is Amy Sanders on the  
15 phone?

16 MEMBER SANDERS: Yes, I'm here.  
17 Sorry. My name's Amy Sanders. I am a geriatric  
18 neurologist at SUNY Upstate Medical University in  
19 Syracuse, New York.

20 And I have no direct disclosures, but  
21 sort of indirectly I'm a member of the American  
22 Academy of Neurology Quality and Safety

1 Subcommittee which has developed measures, none  
2 yet directly related to palliative care that are  
3 standalone, although there is a measure about  
4 suggesting advanced care planning for dementia  
5 patients that is part of a measurement that is  
6 currently in development.

7 And I obviously participate in  
8 advanced care planning discussions with my own  
9 patients, but that's it.

10 MS. HAMMERSMITH: Okay, thank you.  
11 Alice Lind.

12 MEMBER LIND: Hi. This is Alice Lind.  
13 Sorry about my terrible voice. I'm at the  
14 Washington Medicaid agency called the Health Care  
15 Authority, and I have no disclosures to report.

16 MS. HAMMERSMITH: Okay, thank you.  
17 Bob Archuleta.

18 MEMBER ARCHULETA: Yes, Bob Archuleta.  
19 I'm a medical director of Noah's Children Hospice  
20 and Palliative Care, have been for 19 years.  
21 It's now a program of the Bon Secours Catholic  
22 health care system, and I have nothing to

1 disclose.

2 MS. HAMMERSMITH: Thank you. Eduardo  
3 Bruera.

4 (No response.)

5 MS. HAMMERSMITH: Okay, all right.  
6 Thank you, everyone, for those disclosures. Do  
7 you have any comments or questions of each other  
8 based on the disclosures this morning?

9 Okay. Before I leave you, I just want  
10 to remind you that in order to make our conflict  
11 of interest process work, we rely on all of you  
12 as committee members.

13 So if during the discussion you think  
14 that you may have a conflict of interest, you  
15 think that a committee member has a conflict of  
16 interest or is behaving in a biased manner, we  
17 ask you to speak up in real time. You can do  
18 that in the meeting if you wish.

19 If you don't want to do that you can  
20 approach your chairs who will work with NQF staff  
21 or you can approach NQF staff directly. And I  
22 also just want to say that the advice that Sean

1 gave you was dead on about how to discuss things  
2 within the meeting.

3 So thank you very much, and have a  
4 good meeting.

5 MS. JOHNSON: So good morning,  
6 everybody. Thank you again for coming. It's my  
7 pleasure to go over our portfolio with you, and  
8 just remind you of a few things in our evaluation  
9 process before we really delve in and get into  
10 the measures.

11 Sean stole some of my thunder though,  
12 so that's okay, just wanted you to know. Let's  
13 go to the next slide, please.

14 So we want to do a portfolio review  
15 basically to make sure that you understand what  
16 we have in our portfolio. And when we talk about  
17 our portfolio, we talk about all of the measures  
18 that are endorsed by NQF in a particular area.

19 You guys are only seeing some of them  
20 in this particular project and that may have to  
21 do with timing or what-have-you, but for this  
22 project we're looking at measures related to

1 palliative and end-of-life care.

2 Our measures that we endorse should be  
3 useful for accountability and public reporting  
4 purposes for any population in any setting of  
5 care. We will be looking at assessment in  
6 management, physical, psychological and spiritual  
7 aspects of care. We have a couple of care  
8 planning measures that we'll be looking at,  
9 appropriateness of care measures, and the new  
10 ones are the experience-of-care measures from the  
11 CAHPS survey.

12 We currently have more than 36  
13 endorsed measures within the area of palliative  
14 and end-of-life care, and you'll see in a few  
15 minutes why I had to say more than 36 rather than  
16 give you an actual number. Let's go to the next  
17 slide.

18 So as Sean as mentioned, this is not  
19 our first foray into this topic area. Ten years  
20 ago now we actually pulled together a group, and  
21 I'm not sure if anybody was on that original  
22 group. Was anybody on the 2006 group? Doug was,

1       okay, great. Welcome back, Doug.

2               As part of that -- and Cleanne, okay,  
3       and Sean. Oh my. See I should remember these  
4       things, and I apologize that I don't.

5               So in that work the group came up with  
6       a measurement framework, and we'll talk about  
7       that a little bit more later. It was a very  
8       comprehensive framework. It discussed scope,  
9       specifically recipients of care, the various care  
10      settings, the professionals who provide that  
11      care.

12              It talked about structural elements of  
13      care, for example, having team-based care, having  
14      educational programs, et cetera. It articulated  
15      the domains of care, I believe from the National  
16      Consensus Project domains. It talked about  
17      levels of measurement and outcomes.

18              So again, a very comprehensive  
19      framework, and along with the framework that  
20      committee also came up with what we call  
21      preferred practices, 38 preferred practices that  
22      were organized by the domains and the IOM

1 dimensions of care, and those practices are  
2 actually still NQF-endorsed.

3 We endorsed those practices, so maybe  
4 one of the things that we'll talk about later  
5 today or probably more tomorrow is what do we  
6 need to do with those preferred practices? Have  
7 they kind of done their job and they can go? Do  
8 we need to keep them? Do we need to revisit  
9 them? So that'll be some of the work that we'll  
10 talk about tomorrow.

11 In 2012, we pulled together what we  
12 called a steering committee at the time. It was  
13 a temporary committee, and during that project 14  
14 measures were endorsed.

15 And you're seeing, I think, most of  
16 those come back as what we call maintenance  
17 measures this time around, so having another look  
18 at them four or five years later to see if they  
19 still meet NQF's criteria for endorsement.

20 Finally, we have a measure  
21 applications partnership, PAC/LTC workgroup.  
22 Let's see if I can remember what PAC/LTC is.



1 It's post-acute care/long-term care workgroup,  
2 and they give advice and feedback to HHS on  
3 programs for post-acute care and specifically  
4 hospice.

5 So in 2012 that group actually wrote  
6 a paper. Had a meeting and came up with some  
7 strategy and they noted several gaps in care.  
8 They noted what we had at the time, and that was  
9 pretty much going on at the same time that the  
10 endorsement project was going on.

11 So back then there wasn't a tremendous  
12 lot of measures, and that comes through in that  
13 report. But we have MAP meetings every year, so  
14 we get ongoing feedback from the MAP about these  
15 measures.

16 And let me see if I can remember who's  
17 on the MAP. I know Sean is on the MAP and he is  
18 on the hospital workgroup. And Alice, I believe,  
19 you're on the PAC/LTC or are you on duals?

20 MEMBER LIND: I am on duals.

21 MS. JOHNSON: You're on duals, okay.

22 All right, so we may not have anybody on the MAP

1       workgroup.

2                   You'll notice in some of the  
3       preliminary analyses that we've provided you, in  
4       the use and usability section, we talked about  
5       MAP feedback. So this is part of what the MAP  
6       feedback is. If you would like to know more  
7       about MAP and what it does and that sort of  
8       thing, we're happy to explain that to you. We  
9       did a little bit of that in your orientation.

10                  It's probably not critical that you  
11       know that, but it is feedback from folks similar  
12       to you who are interested in measures for  
13       particular programs run by CMS. Go to the next  
14       slide.

15                  So this is a diagram that I'm sure  
16       everybody's familiar with. We see palliative and  
17       end-of-life care as being on a continuum  
18       alongside, often, disease modifying treatment  
19       with the idea that palliative care can be  
20       provided at any time during a condition or  
21       illness, but often it steps up as the disease  
22       progresses.

1           At some point along that trajectory we  
2 start talking about end-of-life care, and we also  
3 realize that end-of-life care actually goes  
4 beyond the death of the patient and there is  
5 grief and bereavement support for family members.

6           So I will be interested in hearing if  
7 anybody feels like that this particular diagram  
8 is outdated, outmoded, or is it still good to use  
9 as an illustration of what we mean by palliative  
10 and end-of-life care. Let's go to the next  
11 slide.

12           So first of all, apologies. You can  
13 see that I'm not a graphics designer, and I'm not  
14 even sure that you can read this. But the idea  
15 here is we wanted to have a measurement  
16 framework, so we still have the framework that  
17 you guys -- some of you, Cleanne and Doug, Sean,  
18 created in 2006.

19           But that one was extremely  
20 comprehensive. There wasn't a picture, and we  
21 were wondering if we need to modify it in any  
22 way, can we draw it out. This is where we landed

1       so far. Notice the word draft. We'll be getting  
2       your feedback as to whether you think, you know,  
3       is this the way we want to go, do we want to do  
4       something else, what the picture looks like. We  
5       have graphic people here that could draw us a  
6       pretty picture.

7               But the idea here is that the patient  
8       and family are at the center of the care. We  
9       have kept the NCP domains of care. You can see  
10      those, the psychological, physical, cultural,  
11      social, et cetera. Those are in the next ring  
12      out.

13             We're recognizing the various settings  
14      of care and we have five of them there --  
15      inpatient, outpatient, hospice, home, and SNFs,  
16      although I should change that to NFs, sorry. And  
17      then the outer environment if you will is end-of-  
18      life care, palliative care, bereavement care, so  
19      those may or may not be quite the right ones.

20             The idea of having a measurement  
21      framework is to help us understand and categorize  
22      or classify the measures that we have and the

1 measures that we don't have.

2 So we want to be able to use something  
3 like this to help us kind of quickly get our  
4 minds and our hands around what is there and what  
5 isn't. And that's the idea of the framework.  
6 Let's go to the next slide.

7 So what is in our portfolio? I think  
8 I talked about these in our orientation but I'll  
9 talk about them again just to bring them back to  
10 your mind. Most of the measures that we have are  
11 around physical aspects of care, and of those,  
12 most of them are dealing with pain.

13 And all 14 of these -- no, I take that  
14 back. Some of the pain measures we'll be looking  
15 at in this project, the two dyspnea measures and  
16 the -- I called it constipation. It's the bowel  
17 regimen measure we will be looking at in this  
18 project.

19 We have a couple of health-related  
20 quality of life measures and a couple of cultural  
21 aspects of care measures. Those -- the stars  
22 indicate that they are not in this project. They

1 are in other projects, so we won't be spending  
2 much time on them other than I wanted you to know  
3 that they exist. They are out there.

4 We have the spiritual, religious and  
5 existential aspects of care. We have the one  
6 measure right now for that in the hospice and  
7 palliative care setting.

8 We have three measures that I have  
9 placed under ethical and legal aspects of care.  
10 They are specifically related to care planning.  
11 Now one could argue that, you know, I put them in  
12 the wrong domains. It's probably not worth an  
13 argument. I can move things around if you want  
14 me to. I'm not, you know, totally wedded to all  
15 of these. Two of the care planning measures are  
16 part of your purview today. Let's see the next  
17 slide.

18 Care of the imminently dying patient,  
19 we have six of those and they are all what I've  
20 noted as appropriateness of care measures. These  
21 are the ones, you know, ED use in the last 30  
22 days of life, ICU use, et cetera.

1                   And then we have experience of care  
2 measures, and this is where it got tricky.  
3 Notice I didn't have an N there. And I did this,  
4 really, because I'm considering some of the other  
5 measures from the various CAHPS surveys as part  
6 of the portfolio even though they aren't  
7 specifically related to palliative or end-of-life  
8 care, but it could be encompassed in those  
9 things.

10                   So we have CAHPS measures for  
11 hospital, both adult and child clinician groups,  
12 dialysis facilities, home health, and nursing  
13 facilities.

14                   So just like the hospice CAHPS  
15 measures that are in the project today and  
16 tomorrow, each of these measures or instruments,  
17 I should say, have several, sometimes 10, 11,  
18 sometimes a few fewer, performance measures  
19 underneath. And they all are very similar in  
20 ways, communication, et cetera, respect, things  
21 like that. So I have put them in our portfolio  
22 for now.

1           We also have two other experience of  
2     care measures, the bereaved family survey and the  
3     family evaluation of hospice care. Both of those  
4     were evaluated about a year and a half ago in our  
5     person and family-centered care projects.

6           One reason is because they were what  
7     we call patient-reported outcome-based  
8     performance measures, and we had a project that  
9     looked only at those kinds of measures and it had  
10    been a while so the timing worked out. We didn't  
11    know that we would have a palliative care project  
12    at the time, so they were slotted with that one.  
13    Okay, let's go to the next slide.

14           So gaps in our portfolio, so based on  
15    the framework, that kind of greenish circle that  
16    you saw, it's really easy to see that some of the  
17    domains of care are not really represented,  
18    particularly the social aspects, and for care of  
19    the imminently dying I believe all the measures  
20    that we have right now are limited to cancer  
21    patients only. So that is a gap that, you know,  
22    we probably may need to fill.



1           We do not have measures specific to  
2           bereavement care or measures that are applicable  
3           specifically to the family or caregiver. So the  
4           CAHPS measures ask the caregiver about the care  
5           that was given to the patient, but there's  
6           nothing yet that actually measures the caregiver  
7           themselves or their experiences.

8           From the MAP work articulated in the  
9           2012 work, and to some extent repeated more  
10          recently, they noted gaps in terms of access to  
11          care particularly palliative care. They talked  
12          about need for goals of care and shared decision-  
13          making, and also we have no costs of care  
14          measures.

15          So those are at least some of the  
16          gaps. Tomorrow we'll be talking a lot more about  
17          gaps and about strategies for how we want to  
18          start thinking about filling some of those  
19          measurement gaps. Next slide, please.

20          So Sean has already -- this is some of  
21          the thunder that he stole so I don't really have  
22          to go over this too much. Some of your

1 responsibilities as standing committees is to  
2 provide input on the relative framework or  
3 frameworks. You may know of other frameworks  
4 that you think would do better, so we'll be  
5 talking about that tomorrow as part of our  
6 discussion, and I really do want to hear what you  
7 think about that.

8 The other thing that I wanted to  
9 highlight from here is you really are overseeing  
10 our portfolio of palliative care and end-of-life  
11 care measures, so with that we want you to think  
12 about the portfolio as a whole.

13 You're going to be evaluating the  
14 individual measures, but keep them in context of  
15 what's out there, okay. That's what we want you  
16 to do. We want you to know what's going on in  
17 the topic area so I've shared some of those  
18 things with you, and really we want you to think  
19 about and provide us feedback again -- mostly  
20 tomorrow -- about how we want the portfolio to  
21 evolve, okay. Let's go to the next slide.

22 So this is a bit of an example. So

1 remember I said that we had 11 pain measures in  
2 the portfolio. What you see here is ten of  
3 those. The 11th one is kind of a different  
4 animal so I didn't include it here, but what you  
5 see here is we have several different process  
6 measures as well as a couple of outcome measures.  
7 We have them across settings.

8 So part of the question when you're  
9 thinking about the portfolio as a whole is, you  
10 know, once there's outcome measures do we still  
11 need process measures? We're not saying that we  
12 don't, but we're saying think about it, okay.

13 Hospice, hospital, home health, et  
14 cetera, for the home health and the nursing  
15 facility settings those are constrained to some  
16 extent by the assessment instruments, the MDS and  
17 the OASIS, but the other ones maybe aren't so  
18 much.

19 So do you really need screening  
20 measures, for example, different screening  
21 measures in the different settings? So again  
22 another thing to think about, maybe you do, but

1 these are some of the conversations that we want  
2 you to think about and that we'll have later  
3 today and possibly tomorrow. Next slide.

4 So overview of the evaluation process,  
5 I just want to remind you of a few things. Let's  
6 go to the next slide. Your role is as a proxy  
7 for our membership, working with us to achieve  
8 the goals of the project, and for today that  
9 means getting through all of our measures as Sean  
10 has mentioned before.

11 You will evaluate each measure against  
12 each of the criterion and you'll rate the  
13 measures. And I believe everybody was able to  
14 attend the workgroup calls so you had at least a  
15 chance to practice and to think about those  
16 things. Today you'll actually be voting, and  
17 Jean-Luc and Rachel will take us through that.  
18 You have your clickers.

19 You'll be making recommendations to  
20 NQF membership about suitability for endorsement.  
21 That's what your job today is to do. As I  
22 already mentioned, you will be the overseers of

1       our portfolio of these measures.

2               Finally, select two-year or three-year  
3 terms. So this is what we call a standing  
4 committee, what that means is we want to have  
5 continuity over time. So we don't want you guys  
6 to go away after tomorrow and you're done with  
7 us. We want you to hang around for a while.

8               So what we're going to do probably  
9 tomorrow is we're going to pass the hat, and  
10 we're going to let you reach in and choose a two-  
11 or a three-year term, okay, so it'll be random.  
12 If you don't want to have a three-year term, let  
13 us know if you'd rather choose the smaller term.  
14 Once your term is over there is a possibility to  
15 re-up for another term as well, so just FYI.  
16 That'll be a little fun tomorrow. Okay, next  
17 slide.

18               We have a few ground rules for today's  
19 meeting. I think there's really nothing here  
20 that is surprising. I think Sean has hit all of  
21 these things. I'll just pause for a second and  
22 see if anybody has any questions about ground

1 rules or anything like that. Do these look  
2 reasonable to everybody? Okay. Next slide,  
3 please.

4 So measure discussion and voting, the  
5 way that we will be running this portion of the  
6 meeting is for all of the measures -- and forgive  
7 me, I'm going to go to my notes here to make sure  
8 I cover everything.

9 We will start each measure by giving  
10 our developers a chance to introduce the  
11 measures. We are fortunate that our developers  
12 come and interact with us at our various  
13 meetings, and you'll notice that we've actually  
14 provided a place for them at the table. So they  
15 will sit here when they're discussing their  
16 measures.

17 And we've done this so that they can  
18 more easily respond to questions from you guys,  
19 okay. So just like you guys they have their  
20 little tent card and they can put it up if they  
21 have something that they want to ask or input,  
22 and our co-chairs who are facilitating will

1 select them to speak when it fits them.

2 Sean's already mentioned the lead  
3 discussants. You'll be discussing things as we  
4 did on the workgroup calls for each of the  
5 criteria. So we'll ask you to do a brief summary  
6 of the pre-meeting evaluation comments and/or  
7 workgroup discussion, because sometimes the  
8 workgroup discussion went off into other things,  
9 right. So any of those kind of things mainly  
10 emphasizing areas of concern.

11 And what we'll ask you to do and we'll  
12 work through it in our first measure, but we'll  
13 have you start with evidence and talk about  
14 evidence and then stop, and then we'll have  
15 discussion, okay. And then when it's time to go  
16 back and we've voted or done whatever we needed  
17 to do, then we'll go back and somebody can talk  
18 about gap. So we'll proceed in the direction of  
19 our criteria.

20 You'll recall that we have, as staff,  
21 provided preliminary ratings for you. Again  
22 those are not binding on you. They were intended

1 to be used as a guide to facilitate discussion,  
2 so we just want to make sure that you understand  
3 that it's not binding. And again the lead  
4 discussants and the workgroup discussants were  
5 the ones who did the really deep dives, but we  
6 really want everybody to be able to discuss and  
7 contribute to all of the measures. Okay, let's  
8 go to the next slide.

9 Overview on voting, so I've already  
10 mentioned this. We'll vote by criterion in the  
11 order that's presented. We have some of our  
12 criteria are must pass, some are not.

13 At the end there will be a vote for  
14 overall suitability for endorsement. You guys  
15 did not do that vote or discuss that on the  
16 workgroup calls, so that'll be new from what you  
17 did before, okay.

18 If a measure actually fails on one of  
19 the must pass criteria, then we stop discussion  
20 and voting. So if something goes down on  
21 evidence that's it, we do not keep going, all  
22 right. We'll just go to the next measure. Let's



1 go to the next slide.

2 Now as a reminder for those of you who  
3 are totally new to the process this isn't a new -  
4 - everything's new to you, right? But those of  
5 you who have been around for a while, we are  
6 treating maintenance measures a little  
7 differently than we have done in the past and our  
8 new process is listed on the slide, less emphasis  
9 on evidence if it's unchanged.

10 Okay. Now that doesn't mean that we  
11 won't discuss evidence. There will be an  
12 opportunity to discuss it if you want to. You  
13 may want to re-vote on evidence and that's fine.  
14 You may not want to. That is also fine, okay.

15 There will be an increased emphasis on  
16 gap or opportunity for improvement. We're not  
17 making any difference in the way that we're  
18 treating our specifications. Specifications are  
19 always something we want to look very closely at  
20 and make sure we understand and are comfortable  
21 with those.

22 That said, there is less emphasis on

1 reliability and validity testing unless that  
2 testing has not been updated. So if the  
3 developers have not updated their testing, they  
4 haven't done anything new, there may not be much  
5 of a reason to have long, drawn-out discussions  
6 or even votes on those. However, if they did  
7 update their testing then we will discuss and we  
8 will vote. Okay.

9 Feasibility emphasis is unchanged, but  
10 we have increased the emphasis on usability and  
11 use. Again this is for our maintenance measures.  
12 And just again to repeat. Discussion and/or vote  
13 on evidence, reliability and validity may not be  
14 needed. Let's go to the next slide -- and don't  
15 worry about it. We will walk you through all  
16 those. We'll point out when you may want to  
17 think about it or not think about it, so we'll  
18 help you with that.

19 A couple of other considerations, I  
20 think we touched on this in at least one or two  
21 of the workgroup calls. We do have a possible  
22 exception to the evidence subcriterion that you

1 can invoke so that might be something that we  
2 need to do.

3 And endorsement with reserve status,  
4 this is a special status. It is an endorsed  
5 status but it's pretty much an inactive status  
6 for measures that are topped out. That means  
7 that everybody's doing so well that there's  
8 really not anymore opportunity for improvement.

9 The caveat with that is that the  
10 measures have to pass all of the other criteria,  
11 and I'm not sure that reserve status is going to  
12 be an option. It might not be something we need  
13 to talk about, but I wanted to alert you that it  
14 might come up, and if it does, I'll give you more  
15 details when we get there. Let's go to the next  
16 slide, please.

17 So voting tools, and in a minute I  
18 think Jean-Luc is actually going to do a practice  
19 session. I don't know if we want to do it now or  
20 if we want to do it closer to time, but you will  
21 have a tool. You have a remote clicker. And --  
22 yes, Sean is demonstrating our clicker.

1                   Those who are on the phone are  
2 actually going to be communicating with Jean-Luc  
3 and Rachel and they will be casting their votes  
4 for them. So you'll see Jean-Luc and Rachel  
5 clicking. That's because they have their --  
6 we're not padding the votes. We will be taking  
7 those from our remote members.

8                   So the instructions are to point  
9 towards Jean-Luc. The remote will briefly  
10 display your choice and basically you can click  
11 that thing as many times as you want. It's going  
12 to record and keep the very last vote. I'm  
13 correct on that, right, Jean-Luc? Okay, great.  
14 Let's see the next slide.

15                  Now let me tell you about consensus  
16 before we get to our little fun exercise here.  
17 Consensus, what's it mean to pass, right? So  
18 first of all we have to have a quorum. We have  
19 to have at least 66 percent of our committee, and  
20 looking around we do have that so we don't have  
21 to worry about that.

22                  It can get a little hairy toward the

1 end of Day 2, you know, when people have flights  
2 to catch and whatever, so we do pay attention to  
3 how many people are voting. We want to know that  
4 denominator so we can get our percentages.

5 To be recommended, measures must have  
6 greater than 60 percent of the committee yeses.  
7 And just to remind you, a yes or a pass is high  
8 or moderate together. If it's less than 40  
9 percent passing then something's not recommended.

10 And that lovely area, 40 to 60,  
11 inclusive, is what we're calling consensus not  
12 reached, and you'll hear us use the term gray  
13 zone, perhaps, if any of the votes fall in that  
14 gray zone. Any measures that fall in the gray  
15 zone, we will actually move forward. So if we're  
16 voting on evidence and the votes land in the gray  
17 zone, in this consensus not reached zone, we will  
18 continue the discussion and go on to the next  
19 criteria and keep going even though it hasn't  
20 officially passed, okay.

21 So our must pass terminology is a  
22 little bit maybe not as accurate as it used to be

1       when we instituted the gray zone.   Next slide.

2               All right, that's it.   Jean-Luc, let's  
3       go ahead and do our little voting exercise.

4               MR. TILLY:   Sure, as Karen described,  
5       just take your clickers, and the polling is now  
6       open for what does CDP stand for, four options.

7               MS. ROILAND:   And again you have to  
8       point them at Jean-Luc to get the computer to  
9       register the vote.

10              MS. JOHNSON:   Hopefully you're seeing  
11      your clicker light up.   If you're having a  
12      problem, let us know.   You can see in that circle  
13      there, 22 people have voted.   I think --

14              MR. TILLY:   Yes, just one time is  
15      good.   So we have 23 votes, which is what we're  
16      looking for.   All right, so the results are 2 for  
17      committee development program, 17 for consensus  
18      development process -- congratulations -- 2 for  
19      careful deliberation process, if only, and 2 for  
20      consensus development program.

21              MS. JOHNSON:   Okay, thank you, Jean-  
22      Luc.

1                   And before we hand it over to Sean to  
2                   take us through our first measure, I know we had  
3                   at least one new person come in, so -- hi, Linda.  
4                   You weren't here in our disclosure process, so  
5                   can you just introduce yourself and let us know  
6                   if there's any potential conflicts or things that  
7                   you'd like to disclose.

8                   MEMBER SCHWIMMER: Okay. Good  
9                   morning, everyone. I apologize for being late.  
10                  Linda Schwimmer, I'm with the New Jersey  
11                  Healthcare Quality Institute. We're a not-for-  
12                  profit so I think I serve as a consumer role,  
13                  which is a role, and I've no conflicts to  
14                  disclose, no conflicts.

15                  MS. JOHNSON: Thank you, Linda. And  
16                  on the phone, we didn't have Eduardo earlier. We  
17                  still don't think we have him. Okay.

18                  All right, are you guys ready to jump  
19                  in? All right, Sean.

20                  CHAIR MORRISON: Terrific. So we are  
21                  going to begin with a dyspnea screening measure  
22                  which is 1639. 1638, thank you, from University

1 of North Carolina at Chapel Hill.

2 And as Karen said, the way that this  
3 will go we'll have the measure developer give us  
4 about two to three minutes' overview about the  
5 measure, then I will ask the discussants to go  
6 through.

7 Doug. Is that not what I said?  
8 Dyspnea treatment, sorry. This is, the last time  
9 I did this I didn't need glasses.

10 Dyspnea treatment, I'll ask the  
11 discussants to go through each of the criteria.  
12 After each criteria, we will vote and then we  
13 will move forward.

14 Again just a couple of quick  
15 reminders, if you have a question, tent card goes  
16 up. We will get to everybody, don't worry. When  
17 you finish your question tent card down, and what  
18 everybody will forget is please turn your  
19 microphone on and off.

20 And finally, the folks, Amy, Alice,  
21 and Bob, it is really hard for us to see your  
22 tent cards, so please just jump. Don't be shy,



1 just jump in. I will put you on the list and we  
2 will get to your comment. But just as I said,  
3 don't be shy. Just say I have a comment and  
4 we'll go from there.

5 Did I miss anything, Rachel?

6 Dr. Hanson from the University of  
7 North Carolina.

8 MS. HANSON: Thank you all so much.  
9 It's a delight to be here after a very early  
10 morning flight from North Carolina.

11 I am going to start, because this is  
12 the first of a series of measures that I'm  
13 measure steward for, to give a little context of  
14 the development of that particular group. So  
15 forgive me and I promise I will never talk this  
16 long again when introducing measures, but just  
17 wanted to give a little context.

18 So the 1638 dyspnea treatment measure  
19 is one of a group of quality measures that were  
20 developed in the PEACE project. And the PEACE  
21 project was funded by CMS in preparation for  
22 quality measurement in the hospice population,

1 but a very specific charge in the PEACE project  
2 was to select quality measures that were relevant  
3 to both hospice and palliative care populations.

4 So when these measures were put  
5 forward for NQF endorsement, we utilized  
6 initially the data that came from the PEACE  
7 project itself in developing and initially  
8 testing the measures in the hospice population,  
9 and then we augmented that with data from a  
10 second deployment of a subset of the PEACE  
11 measures.

12 All of the currently endorsed measures  
13 were included in that subset to collect data in a  
14 hospital-based palliative care population. So in  
15 your materials in which you see the original  
16 submission of this group of measures, you see  
17 data both from originally a hospice group and  
18 separately a palliative care data source.

19 In this maintenance submission, we  
20 have primarily provided data that is new for the  
21 hospice population because these measures have  
22 now been incorporated as originally intended in

1 the HIS, in the hospice quality reporting system.

2 The measures themselves are also being  
3 incorporated in a variety of ways in palliative  
4 care populations although none of that data is  
5 ready for submission at this time. And I'll just  
6 give a general comment about that and then when I  
7 talk about specific measures, I can give you a  
8 little bit more about that.

9 So in the more proximate future,  
10 several of the PEACE measures are being utilized  
11 in a CMMI project, CMMI-funded project, an  
12 innovation project that is collecting data on a  
13 palliative care population in a variety of  
14 settings.

15 There is some data collection moving  
16 forward through the PCRC, the Palliative Care  
17 Research Cooperative group, on some of these  
18 measures again in a diversity of settings with  
19 palliative care populations.

20 And then in the more distant future,  
21 these measures, some of these PEACE measures are  
22 being incorporated in a QCDR, so in a qualified

1 clinical data registry which is being submitted  
2 to CMS, and this fills a gap in palliative care  
3 practice, specifically, where outside of a  
4 hospital setting, palliative care providers are  
5 struggling to demonstrate quality measures to  
6 meet new payment criteria that they must meet.  
7 And at the moment they're forced to use quality  
8 metrics that are really not relevant to the  
9 palliative care population.

10 And then, finally, these measures are  
11 also being incorporated in the evaluation process  
12 of the large Medicare demonstration project that  
13 is just now being initiated but which will test a  
14 model of concurrent hospice organization-  
15 delivered palliative care along with disease-  
16 directed treatment in a concurrent care model  
17 that will actually match a lot of what happens  
18 currently in palliative care practice.

19 That project and data from that  
20 project is probably five years hence. But I want  
21 you guys to have that landscape just to  
22 understand the context, because I know that one

1 of the initial questions is why are there two  
2 data elements that segregate the hospice and  
3 palliative care populations.

4 So the dyspnea treatment quality  
5 measure, hopefully you all see this in terms of  
6 its specifications, but basically it's a  
7 percentage of hospice or palliative care patients  
8 who initially screen positive for dyspnea as a  
9 clinical problem and who then, the numerator  
10 criterion, go on to receive treatment for their  
11 dyspnea within 24 hours' time.

12 This quality measure was submitted to  
13 NQF as a paired measure, and you'll hear that  
14 from me again, with dyspnea screening. In  
15 developing these PEACE measures, we made the  
16 assumption that the process included screening  
17 for a symptom first, which is what we do by  
18 simply asking if it's present and asking if it's  
19 a problem for the patient, if it's something  
20 that's distressing to them, and then going on to  
21 assessment and treatment based on that  
22 establishment of a denominator population.

1           So that's what this measure reflects  
2     and it's paired with a dyspnea screening measure  
3     that you'll hear about. In this submission, we  
4     are asking for a modest change in the  
5     specifications of the measure.

6           So when originally submitted, this  
7     measure excluded individuals enrolled in hospice  
8     care who were in hospice for seven days or less.  
9     That was at the advising of the expert panel that  
10    we put together for the PEACE project itself,  
11    thinking that perhaps seven days were necessary  
12    for hospices to accomplish dyspnea treatment, but  
13    there was a lot of concern that excluding that  
14    population, as we all know, excludes a very high  
15    percentage of people who are enrolled in hospice.

16          So in this maintenance submission we  
17    are asking and have provided data to indicate  
18    that that exclusion can be removed so that it can  
19    apply to all persons enrolled in hospice  
20    regardless of length of stay.

21          I think I'll stop there. There may be  
22    other questions or comments. Just to ask the

1 chairs, do you wish for me to stay here during  
2 the discussion?

3 CHAIR MORRISON: Yes, afraid so.

4 MS. HANSON: Glad to do so.

5 CHAIR MORRISON: Questions on process  
6 before we take a deep breath and begin? Indeed  
7 not. Okay, so I have Cindi and Ruth as the  
8 discussants.

9 Cindi, do you want to walk us through  
10 the evidence piece? We'll start with evidence.

11 MEMBER PURSLEY: Okay, can you hear  
12 me? Okay. And just so you know, I may be from  
13 Colorado -- this is a cough drop not chew.

14 This measure is for patients that  
15 screen positive and have treatment initiated  
16 within 24 hours of the screening. It's a process  
17 measure. It's in for maintenance.

18 They do have the results from the last  
19 -- gosh, I'm going to say almost three years now  
20 from the hospice item sets submissions, and so  
21 the data is there for this measure.

22 So the evidence initially and the

1 evidence that's been collected still supports  
2 this measure.

3 CHAIR MORRISON: Ruth? Where's Ruth?  
4 There she is. Anything to add for --

5 MEMBER MACINTOSH: The evidence  
6 remains but it has been updated by the developer  
7 with two new guidelines, so there's plenty there.

8 CHAIR MORRISON: Well, good. And we  
9 don't have to vote, right, because -- sorry.

10 MS. JOHNSON: So the question that we  
11 would have for you guys as the committee is do  
12 you know any other evidence for this that would  
13 be contradictory in nature?

14 So they provided updated evidence. It  
15 pretty much just strengthened the story from  
16 before. If you don't know of anything new that  
17 would make you change your mind or shed some kind  
18 of doubt on this measure, then we could decide  
19 not to do any further discussion and not to vote.

20 CHAIR MORRISON: Anything new, folks?  
21 Terrific. Then why don't we move to the next  
22 criteria which is the opportunity for



1 improvement.

2 And again on Cindi and Ruth, and just  
3 a reminder and I will do this just for the  
4 beginning, this first measure. This is  
5 describing any data on current performance,  
6 opportunities for improvement, any data on  
7 disparities and any other issues in terms of  
8 questions to the committee from the preliminary  
9 analysis.

10 So can we go back to Cindi?

11 MEMBER PURSLEY: Yes. The -- from a  
12 user standpoint an area of an improvement would  
13 be the way the question is asked. It's asked if  
14 treatment, if the patient screens positive for  
15 dyspnea, was treatment initiated within 24 hours.

16 And what I found is that my staff, who  
17 are very literal, if the patient was on treatment  
18 and they did not initiate a new treatment, then  
19 they answered it as no, and it made it look like  
20 the patient screened positive for dyspnea but did  
21 not receive treatment.

22 So my recommendation for an

1 opportunity would be, for example, with the  
2 bowel, the opioid bowel question, it says did you  
3 continue or initiate a bowel program for a  
4 patient on opioids? Any my suggestion would be  
5 to add, did you continue or initiate treatment  
6 for dyspnea?

7 CHAIR MORRISON: And I guess, Ruth,  
8 your comments?

9 MEMBER MACINTOSH: I agree with Cindi.

10 CHAIR MORRISON: Open for discussion.  
11 Karl.

12 MEMBER STEINBERG: I also agree, but  
13 I might say initiate or continue instead of  
14 continue or initiate.

15 CHAIR MORRISON: Okay, others? Laura.

16 MS. HANSON: I'll just point out, and  
17 I do agree that that's language out of the HIS in  
18 its implementation, which I think shows for all  
19 of us some of the complexity of implementation of  
20 quality measurement in real-world practice, the  
21 use of the term initiate was very purposeful in  
22 indicating that once the hospice provider assumes

1 responsibility for the care of the individual,  
2 they initiate all care. They initiate it.

3 However, from a provider's  
4 perspective, it may well be that one continues a  
5 treatment that was begun prior to assuming  
6 responsibility for care of the patient.

7 So it's an implementation issue, I  
8 think, rather than a specification issue. It  
9 doesn't change the measure specification, but it  
10 shows the subtlety of implementation.

11 CHAIR MORRISON: Arif.

12 MEMBER KAMAL: So, you know, the  
13 concern here is that it's a patient presumably  
14 who's been on a stable regimen of something for  
15 dyspnea, and despite that has, you know, moderate  
16 to severe dyspnea, you know, on admission to  
17 wherever they are, hospice or the hospital,  
18 which, you know, in terms of expectation-setting  
19 may be a four out of ten as to where they're  
20 going to be and where the best of our evidence  
21 says that they may go.

22 At the same time they're saying we're

1 just going to continue on what they had before  
2 with no, you know, sense of trying to tweak  
3 things or modify things for find things or add  
4 things. It is a little troublesome to me, too.

5 So I think, you know, initiation or a  
6 continuation with the spirit that we are really  
7 trying to maximize what's possible is really, I  
8 think, what we're trying to get at.

9 So I don't think it can be purely, you  
10 know, the continuation part. I think the  
11 initiation is actually a really important part of  
12 it, because you're saying somebody has a  
13 remarkable amount of dyspnea that's being noted.

14 CHAIR MORRISON: Other comments,  
15 thoughts?

16 So I'm going to turn to Rachel for a  
17 second and ask, because at this point for this  
18 particular area sometimes we would put forward a  
19 measure -- or, sorry, a motion not a measure that  
20 would be voted on to change to identify the gap.

21 And I'm going to ask Rachel, would  
22 this be something that we would put forward? Is

1       this a recommendation?

2                   MS. ROILAND:   And I'm actually going  
3       to turn it over to Karen to answer that one.

4                   MS. JOHNSON:   We can certainly put  
5       that in the minutes of our report.   And Laura has  
6       heard, and it sounds like it's something -- let  
7       me make sure I understand.   This is something  
8       that you can actually change in our specs, or  
9       you're saying that it's really, the confusion is  
10      more in the HIS instructions?

11                  MS. HANSON:   It really is in the HIS  
12      instructions, and that's what I mean by  
13      implementation.   This would not be a change to  
14      the specifications of the quality measure itself,  
15      but clarifying implementation is a welcome  
16      contribution.   I just want to make that  
17      distinction.

18                  MS. JOHNSON:   And we will reflect it  
19      that way in the report.

20                  CHAIR MORRISON:   Perfect.   So I think  
21      we are -- do we need to vote on this?   There's  
22      nothing to vote on, correct?

1 MS. JOHNSON: Well, you still haven't  
2 actually talked about opportunity for  
3 improvement.

4 CHAIR MORRISON: Oh, yes. I  
5 apologize. Opportunity -- Cindi.

6 MEMBER PURSLEY: Would it be better  
7 served to say initiated or adjusted because it's  
8 then proactive? It shows that you're doing  
9 something.

10 CHAIR MORRISON: Christine.

11 MEMBER RITCHIE: Just as a question  
12 for clarification, when you're talking about  
13 opportunity for improvement are you talking about  
14 adjustment of the measure itself or the gap that  
15 the measure demonstrates?

16 CHAIR MORRISON: I'm sorry, the gap  
17 that the measure demonstrates, not the measure  
18 itself. Yes, I think as Rachel told me we have  
19 an hour, so we're going to let this conversation  
20 go a little longer than I normally would. But  
21 yes, we're looking for opportunities in terms of  
22 gaps and not to rewrite the specs of the measure,

1 per se.

2 Arif.

3 MEMBER KAMAL: Sean, this is going to  
4 come up, and this is to Karen and Rachel, too.  
5 In terms of changing specs, words, phrases, et  
6 cetera, where or if is that germane within the  
7 total agenda of the conversation, because I have  
8 a feeling that's going to come up repeatedly.

9 MS. JOHNSON: Basically, in terms of  
10 your voting you should be voting on the measure  
11 as it's written. However, if you have  
12 recommendations or ideas and it's something  
13 relatively simple, you know, a little  
14 wordsmithing, and if the developer is amenable to  
15 that then they could do that. But you pretty  
16 much have to vote on what you have as is.

17 So we want to make sure that we  
18 capture any of your recommendations, but this is  
19 not, you know, our opportunity to rewrite  
20 measures.

21 CHAIR MORRISON: Laura.

22 MS. HANSON: And I just want to point

1 out that the language in the measure  
2 specification is receive treatment. So I want to  
3 make that distinction. The language in the  
4 specification is receive treatment, which I think  
5 captures very much the intent of what your  
6 concern is.

7 But implementation through the HIS  
8 uses a somewhat different language because of  
9 concern about the passing of responsibility if  
10 somebody comes into hospice, they screen positive  
11 for dyspnea, meaning they have dyspnea as an  
12 active problem on the moment of admission, making  
13 sure, and I think this goes a little bit to  
14 Arif's comment that treatment is initiated within  
15 24 hours to address that symptom distress, but  
16 the specifications for the measure are really to  
17 receive treatment within 24 hours of dyspnea  
18 being identified as an active problem for the  
19 person.

20 CHAIR MORRISON: So I will jump in and  
21 I will not do this again. But I guess, you know,  
22 one of the opportunities in gaps is, as Laura



1 described, in getting the lack of the new  
2 palliative care data that we had that hospice  
3 data are provided, but both in terms of  
4 disparities and how this is performing within the  
5 palliative care population because a third of  
6 hospices are now above the 90th percentile, the  
7 question is whether that is an opportunity or a  
8 gap.

9 Christine.

10 MEMBER RITCHIE: Just so I understand  
11 what you're saying, Sean, you're suggesting that  
12 it could be almost considered to be, quote-  
13 unquote, topped out in the hospice community, but  
14 because we don't have data in the palliative care  
15 community there still probably is a lot of  
16 opportunity for improvement? Is that what I'm  
17 hearing you say?

18 CHAIR MORRISON: That's what you're  
19 hearing me say. And I think we also heard from  
20 the developer that those data will be coming in  
21 shortly, but they're not available now. So thank  
22 you for summarizing that. Yes, that's what I'm

1 saying.

2 MEMBER RITCHIE: And just to follow  
3 on, I mean I would agree with that. I think  
4 there are still some folks in the hospice  
5 community who are not doing so well on this  
6 measure, but by far and away, most are doing  
7 quite well. But we don't have the palliative  
8 care data and it seems like a great opportunity  
9 for us to have that data in the future.

10 CHAIR MORRISON: Last comments?

11 So I'd just go back to the  
12 preliminary, the work that NQF staff did, because  
13 we have to, this now comes up to voting. And the  
14 initial work by staff and the workgroup was that  
15 there was a moderate opportunity for improvement  
16 on this measure. That was the preliminary report  
17 which Rachel just put up, and we now come to the  
18 point where we get to use our clickers.

19 And what we are voting on is whether  
20 there is an opportunity for improvement on this  
21 measure and you get to vote under high which is  
22 1, 2 which is moderate, 3 which is low and 4 is

1       insufficient.

2                   We will take a vote. Please aim your  
3       clicks at Jean-Luc when he tells us to and not  
4       before, otherwise you'll be clicking all day.

5                   MR. TILLY: Sure, you can go ahead and  
6       click now.

7                   MS. ROILAND: And bear with us while  
8       there's a delay. We're just waiting for some  
9       remote participants to vote.

10                  MS. JOHNSON: And while we're waiting,  
11       just a reminder, when you're thinking about gap,  
12       you can certainly look at the performance rates  
13       that are in front of you. You can think about  
14       whether those are high or low.

15                  You can think about whether there's a  
16       lot of variation between the results. You can  
17       also think about whether there are any  
18       disparities in care, so any of those three ways  
19       would be ways to demonstrate opportunity for  
20       improvement.

21                  Amy Sanders, we're still waiting on  
22       your vote. Have you sent something to Jean-Luc

1 or to Rachel? Amy, are you there? We're not  
2 hearing you.

3 OPERATOR: Amy has disconnected.

4 MS. JOHNSON: She may have stepped  
5 out. Let's just proceed without her vote.

6 MR. TILLY: Okay. And the results are  
7 3 for high, 18 for moderate, 1 for low, and zero  
8 for insufficient. The measure passes.

9 CHAIR MORRISON: Well done, folks,  
10 your first vote. So we are going to move on to  
11 reliability and validity, and I'm going to go  
12 back. We're going to flip the order a little  
13 bit.

14 Ruth, can I ask you to talk about  
15 both? We'll start with reliability and then  
16 we'll move on to validity. We have to vote after  
17 each one, right? Let's just talk about  
18 reliability, she says.

19 MS. JOHNSON: And just a reminder too,  
20 under reliability this encompasses specifications  
21 and testing.

22 MEMBER MACINTOSH: Just a minute,

1 please. I apologize. I thought I was doing all  
2 of the screening and Cindi was doing the  
3 treatment, so --

4 CHAIR MORRISON: I can do it whichever  
5 way you would like.

6 MEMBER MACINTOSH: Well, why don't we  
7 let Cindi, why don't we do it that way?

8 CHAIR MORRISON: Cindi, why don't we  
9 start, we'll start with you. So we're on  
10 reliability.

11 MEMBER PURSLEY: Reliability  
12 specifications, they -- it was reliable  
13 initially, and now with the addition of, I think  
14 it's almost 4,000 hospices collected data, I  
15 think that it supports the reliability for  
16 hospice is there. I think the new data they  
17 presented supported reliability.

18 CHAIR MORRISON: Cindi, did you have  
19 anything? I'm sorry, Ruth, did you have anything  
20 to add?

21 MEMBER MACINTOSH: No, the reliability  
22 and reliability testing brings in to what the

1 developer said about changing the specification  
2 to no longer exclude hospice stays of less than  
3 seven days, and I have no problems with that. I  
4 agree with it.

5 CHAIR MORRISON: Open for discussion,  
6 rest of the committee. Christine.

7 MEMBER RITCHIE: Just as a question,  
8 are we, is a sample size of 20 acceptable for  
9 reliability testing for palliative care?

10 CHAIR MORRISON: And I turn to Rachel  
11 to answer that one.

12 MS. ROILAND: I'll take a first stab  
13 at it, and Karen, if you just want to correct me.  
14 We don't have specific standards for how large a  
15 sample size needs to be in any given testing  
16 situation, so it's your assessment of whether or  
17 not that sample size is sufficient.

18 MS. JOHNSON: And the only thing I  
19 would add is we would like to see testing that is  
20 representative, and that's in air quotes, to kind  
21 of encompass the kinds of providers that would be  
22 measured as well as the patients that would be

1 measured.

2 So you just kind of think about the  
3 scope, when you're thinking about rating just  
4 think about the scope of the sample. Twenty may  
5 be fine for some people, and twenty may not be  
6 anywhere close enough for other people so it's  
7 kind of up to you.

8 CHAIR MORRISON: Michelle.

9 MEMBER CAUGHEY: Thank you. That's  
10 the one I've been struggling with is that this is  
11 a measure that is in two different settings, one  
12 of which we have clearly reliable information and  
13 the other really hasn't been tested, and I'm not  
14 even sure that, you know, that the measurement  
15 that's coming hopefully will tell us something.  
16 This is going to be true for a lot of our measures.

17 And so the assumption I'm making is  
18 based on the hospice data set data that it would  
19 be useful in the palliative care inpatient  
20 setting or even outpatient, ultimately.

21 And I just would ask whether that is  
22 what the other committee members are also

1 concluding?

2 CHAIR MORRISON: I've got Christine,  
3 then Paul, then I think Laura will probably  
4 respond.

5 MEMBER RITCHIE: Right, Laura. You  
6 can add this to your list of things to respond  
7 to. So this reliability testing with the 20  
8 charts that were abstracted were, that was in one  
9 hospital, one facility?

10 CHAIR MORRISON: And Paul? Please.

11 MEMBER TATUM: I'll take my finger  
12 off. If one were to vote insufficient, I wonder  
13 if you could walk us through the implications to  
14 the rest of the process on that.

15 MS. JOHNSON: If the majority of the  
16 members voted insufficient -- sorry. If the  
17 majority of the members vote insufficient, then  
18 the measure would not pass reliability. We would  
19 stop discussion. The measure would go down. It  
20 would not be endorsed.

21 This one is, it is a little tricky  
22 because she has two different kinds of testing



1 but we're only asking for one vote. So you can  
2 use your own judgment about how you want to weigh  
3 and balance what you're seeing.

4 CHAIR MORRISON: Let me go to Woody,  
5 and then, Laura, I have the questions for you to  
6 respond to.

7 MEMBER MOSS: Yes, and so this is a  
8 clarification probably going to Laura. This is,  
9 I think, the 20 patients is inter-rater  
10 reliability not the overall sample, and at least  
11 in studies that I've frequently read, inter-rater  
12 reliability isn't just a sub-population it's the  
13 entire sample. So I'm just sort of commenting on  
14 that and seeing what Laura has to say.

15 CHAIR MORRISON: Dr. Hanson.

16 MS. HANSON: Oh boy, bunch of  
17 questions. So let me answer Woody's question  
18 first. So what we did with all the PEACE  
19 measures in the second data collection, second  
20 wave where we were purposefully looking at the  
21 hospital-based palliative care population, is  
22 that we took a random sample of the subjects who

1 were the target of those quality measures, a  
2 relatively diverse population, albeit within a  
3 single institution, and we basically started out  
4 with 20 records in order to see if inter-rater  
5 reliability was valid.

6 And when we hit a kappa, in this  
7 instance, of 0.89, we were satisfied that we had  
8 actually established inter-rater reliability. We  
9 did it in a rigorous manner in the sense that two  
10 independently trained raters were given the  
11 record to abstract and they abstracted all of the  
12 PEACE measures and then we compared their  
13 abstractions.

14 And so it was really the kappa, the  
15 level of agreement that on this quality measure  
16 led us to stop at 20. Could we have done more?  
17 We could have done more.

18 I think the second thing that I'd like  
19 to respond with, I think this is one of the  
20 fundamental challenges, honestly, for our field.  
21 And we face it in how to present the PEACE  
22 measures which were purposely, we were charged by

1 CMS to develop measures that would be relevant to  
2 the hospice population but also to the palliative  
3 care population.

4 The hospice denominator population is  
5 defined by who enrolls in the hospice benefit.  
6 It's easy to figure out. The palliative care  
7 population as we all understand is shifting  
8 sands. The denominator population for palliative  
9 care is changing every year.

10 We are trying to present these  
11 measures as they were originally specified which  
12 is to be measures that are relevant and  
13 applicable to the breadth of that population,  
14 while concurrently acknowledging NQF's dilemma  
15 which is that you'll need to see data that looks  
16 at populations in different settings with  
17 different characteristics in order to believe  
18 that a measure may perform similarly.

19 The gap may be different in different  
20 populations, but the measure itself  
21 scientifically may perform similarly across  
22 settings and across denominator populations.

1 I think for me as a measure developer,  
2 I would argue that these concepts of reliability  
3 are relatively intrinsic to the measure itself.  
4 There are some differences in the way the data is  
5 collected, so a little difference in  
6 implementation that may be important for  
7 reliability, but the specifications of the  
8 measure itself are the same for the two different  
9 data collection methods.

10 I don't envy you your job.

11 CHAIR MORRISON: So I have Paul.

12 MEMBER TATUM: Speaker phone. I can  
13 take my finger off and you can hear me if I lean  
14 in, I think. I'm happy to run through the  
15 algorithm. I find this very helpful.

16 CHAIR MORRISON: Paul, you've got to  
17 make sure -- there you go. Oh, still not close  
18 enough.

19 MEMBER TATUM: I'll move this forward  
20 so I don't have to spend the whole day fighting  
21 this thing. I'm very pleased to run through the  
22 algorithm. It's very helpful to me just noting

1       that the quantity under moderate can be low but  
2       the quality is moderate, and I think this metric  
3       is important.

4               And while we could waffle on the  
5       palliative side of things, that piece about the  
6       quantity of information being low to high is  
7       helpful for me to review that as we talk about  
8       the palliative numbers, and the hospice numbers  
9       are good.

10              I'm not supposed to speak to emotional  
11       advocacy for a metric, but I don't want us to  
12       keep throwing out baby with the bath water of  
13       measures that we desperately need.

14              CHAIR MORRISON: And just a clarifying  
15       question for both Karen and Laura. Laura, you  
16       had said that there would be data available on  
17       the palliative care performance coming forward,  
18       and that was my first question.

19              My second question to Karen is that,  
20       can the committee ask or make a strong  
21       recommendation that those data be presented back  
22       to us if the measure passes on, you know, on high

1 or moderate?

2 MS. JOHNSON: I think that would be  
3 really fair to ask Laura if you are at least  
4 considering presenting not just performance data  
5 but are you planning on doing additional testing?

6 For example, you've done signal-to-  
7 noise at the score level, are you planning on  
8 doing something similar to that?

9 MS. HANSON: Wasn't planning on it,  
10 but I'm here to listen. So I'm happy to take  
11 those kinds of inputs and recommendations.

12 CHAIR MORRISON: Anybody on the phone  
13 have a comment? I see Dr. Ritchie's card going  
14 up. Christine.

15 MEMBER RITCHIE: So this is just my,  
16 so please bear with me. This is my learning how  
17 to figure out how to support, effectively support  
18 sort of this process.

19 So I think nobody would argue that  
20 dyspnea is an incredibly important thing to  
21 measure, and the challenge, Laura, that you  
22 brought up is, of course, one that's very

1 significant and probably one we'll continue to  
2 struggle with throughout the day.

3 But there are two challenges that I  
4 see and I just wanted to get input from Karen and  
5 others about how to navigate these, so one is  
6 around the denominator.

7 So, if anything, just trying to figure  
8 out when we're talking about the denominator  
9 exactly what that denominator is would at least  
10 give me some sort of comfort about how likely it  
11 is that we're going to be able to replicate these  
12 kind of findings elsewhere.

13 And then the second is around the  
14 practice setting and this relates to sort of how  
15 data gets assessed through chart abstraction, et  
16 cetera, based on the setting of care. So, you  
17 know, if you have a certain kind of electronic  
18 medical record then your likelihood for being  
19 able to demonstrate reliability may be much  
20 greater than if you have a different kind of  
21 electronic medical record.

22 And so I'm struggling with those two

1 issues and how much to take them seriously or  
2 just to disregard them, I'm happy to disregard  
3 them but that's what I'm struggling with.

4 MS. JOHNSON: So let me start just  
5 quickly talking about the testing that they did  
6 for the hospital side, right. They provided one  
7 kappa value and we are assuming that that was for  
8 the numerator.

9 And it would be good, Laura, if you  
10 could just tell us for sure that you probably did  
11 some case finding or something and you couldn't  
12 really do a denominator kappa.

13 So I think the question for you guys  
14 is, do you feel like that without seeing data  
15 that you can make an assumption that one could  
16 accurately and reliably, actually I should say  
17 reliably, get that denominator knowing that  
18 different hospitals are going to pulling from  
19 different kinds of EHRs, it's just the world  
20 we're in, and so that's just something you have  
21 to balance there?

22 And I'm sorry, Christine, I forgot



1 your second question.

2 MEMBER RITCHIE: It's really about the  
3 challenge of engaging in reliability testing at  
4 one site when the reliability testing is  
5 predicated on how the charts are abstracted and  
6 what the electronic medical record, or not, looks  
7 like.

8 MS. JOHNSON: So here's the way I  
9 think about reliability testing. I think about  
10 it a little differently if I'm thinking data  
11 element versus score level.

12 For data element it's usually a small  
13 sample. And the idea with NQF is that it at  
14 least gives you a flavor of what can be done.  
15 It's no guarantee that every time you go out into  
16 the world that it will be similar at the data  
17 element level, but it at least gives you some  
18 comfort hopefully if the results are good that's  
19 reasonable.

20 The score level reliability, which  
21 they have not done for the palliative care  
22 hospital setting, the score level reliability is

1 actually a function of the variability and it's  
2 really more a function of the data that we're  
3 looking at.

4 So you can't necessarily say because  
5 the score-level testing in the hospice setting  
6 was high I know it's going to be in the hospital  
7 setting. You can't make that jump, but you can  
8 probably make a jump on the data element side.  
9 That's how I think of reliability testing.

10 So I'm not sure if that's answered  
11 your question or not. Are we getting there?

12 MEMBER RITCHIE: That's the last thing  
13 I'm going to say, or question I'm going to ask.  
14 So the data elements in the hospice setting is  
15 through the hospice item set, Laura, but the data  
16 elements are much more arbitrarily designated in  
17 the hospital because there's not a measurement  
18 tool that's consistent across all settings,  
19 right, or am I misunderstanding that?

20 MS. HANSON: For the hospital-based  
21 palliative care, well, really, hospital-based  
22 serious illness population some of whom had

1 palliative care, specialty palliative care, and  
2 some of them did not, we had a structured chart  
3 abstraction tool. We had training for the  
4 abstractors.

5           So I would argue that it was a process  
6 very similar to the HIS, very similar in its  
7 standardization for the abstraction of the data  
8 elements, the training of the abstractors, so  
9 that they could achieve inter-rater reliability  
10 because they had a standardized approach to the  
11 data collection itself. That's how the kappa of  
12 0.89 happens.

13           It's not the same process. It's not  
14 the identical process to the HIS. When we  
15 collected that data, the HIS did not exist. I  
16 think it does raise a question moving forward,  
17 this convergence question around different forms  
18 of electronic medical records.

19           One of the things that we observed in  
20 the PEACE project which I found to be very  
21 interesting was that we asked for the collection  
22 of denominator data separately from numerator

1 data, so the data that would make you meet the  
2 numerator was separately abstracted in time on  
3 the same instrument but you couldn't tell as an  
4 abstractor that you were picking up the numerator  
5 and the denominator.

6 We tried out what it would be like to  
7 abstract, essentially, did this person with  
8 dyspnea get treatment within 24 hours? Not  
9 surprisingly, if you abstract the numerator and  
10 the denominator at the same moment in time you're  
11 much more likely to meet the quality measure.

12 So how the data is collected is really  
13 important. We tried in both the HIS and in the  
14 way that we collected the palliative care data to  
15 have a very rigorous and very standardized  
16 instrument in order to pull that data.

17 CHAIR MORRISON: I'm going to ask if  
18 there are any last, burning issues around  
19 reliability before we go to a vote. I recognize  
20 that this is confusing. I recognize that it is  
21 complex, and I recognize that there are no easy  
22 answers.

1 I do want to highlight Paul's comment  
2 that if you really get stuck, you have the  
3 algorithm which is extraordinarily helpful in  
4 terms of wading through this.

5 But I think we're ready to vote on the  
6 reliability criteria. And again 1 is high, 2 is  
7 moderate, 3 is low, 4 is insufficient. When  
8 Jean-Luc says go, point your clicker at Jean-Luc.

9 MR. TILLY: Yes, by all means, please  
10 go ahead.

11 MS. ROILAND: Bob, if you're on the  
12 line, if you could send your vote to Jean-Luc, I  
13 would really appreciate it. Thanks.

14 CHAIR MORRISON: Bob, if you're on the  
15 line and still with us, we need your vote.

16 MS. JOHNSON: And Bob, if you can hear  
17 us and you're trying to talk we cannot hear you,  
18 just so you know.

19 MR. TILLY: All right. The results  
20 are zero for high, 20 for moderate, 2 for low,  
21 zero for insufficient, so the measure passes.

22 CHAIR MORRISON: And then I think the

1 last thing just before we move on, as Karen  
2 reminded me that we would like to insert a  
3 comment that we would like to see some of the  
4 specs coming back, if that's okay, Laura, and  
5 even if it's not.

6 So we're going to move on to validity.  
7 And again just to very quickly highlight the  
8 aspects of validity testing, I'm going to do it  
9 just this time. You know, we're looking for the  
10 specifications. Is it consistent with the  
11 evidence testing, similar tests, how it was  
12 tested, and then the results and any threats to  
13 validity?

14 So let me ask, Cindi, you're doing  
15 treatments, right?

16 MEMBER PURSLEY: Yes.

17 CHAIR MORRISON: So let me ask Cindi  
18 to start with this one.

19 MEMBER PURSLEY: Validity testing,  
20 face validity and empirical, we have the 2015  
21 data for hospice. It's extremely high, 1.2  
22 million patients, almost 4,000 hospices. Again

1 for palliative care there's nothing available. I  
2 think that statistically hospice is extremely  
3 high.

4 Do you want to talk about threats?

5 CHAIR MORRISON: Yes, I was going to  
6 say why don't we talk about threats?

7 MEMBER PURSLEY: Okay.

8 CHAIR MORRISON: I'm sorry.

9 MEMBER PURSLEY: The developer has  
10 asked for an exclusion of the seven-day, patients  
11 with a length of stay under seven days be  
12 excluded. This is a very high population for  
13 hospices as we all know.

14 And in testing the validity it was  
15 found that it did not have an impact but it did  
16 offer a higher denominator for the data. So I  
17 think taking that out of this measure, that  
18 exclusion.

19 CHAIR MORRISON: Karen, do you want to  
20 just talk a little bit about face validity?

21 MS. JOHNSON: Sure. Just a reminder,  
22 for the palliative-care setting the developer did

1 do some face validity testing, and those results  
2 are there for you. And NQF does allow face  
3 validity as an indicator of quality as long as  
4 it's done at the score level which it was done.

5 And they also did some construct  
6 validity for that setting. We weren't exactly  
7 sure when we were doing the analysis from the  
8 staff exactly how that analysis was meant to  
9 demonstrate validity.

10 So one that might be something that  
11 Laura could help us understand a little bit more  
12 because with face validity moderate is really as  
13 high as you can go at least for that side, but  
14 the construct validity could be at score level  
15 and that might get you a different rating.

16 CHAIR MORRISON: Laura.

17 MS. HANSON: So for all of the PEACE  
18 measures for this sample of 500-plus patients in  
19 a single hospital site, my own institution, what  
20 we did for construct validity would typically or  
21 frequently be tested by an a priori hypothesis  
22 that says this measure measures this construct.



1 And I have another measure over here that also  
2 measures that same construct, so I'm going to  
3 collect both and then see how well aligned they  
4 are.

5 We didn't have anything like that to  
6 use for this quality measure, so as a consequence  
7 what we decided to do was a priori hypothesize  
8 that individuals with serious illness who  
9 screened positive for dyspnea would be more  
10 likely to meet the numerator condition for this  
11 quality measure, and that's true for the others  
12 in the set, if they were seen by a specialty team  
13 in palliative care than if they were not.

14 So we basically used that hypothesis  
15 as a kind of proxy for construct validity, saying  
16 this is a priority for the expertise of the  
17 interdisciplinary team and therefore we would  
18 expect the measure to be met more often.

19 In the case of this measure you can  
20 see that there was an incremental difference but  
21 not one that was statistically significant.

22 CHAIR MORRISON: Other comments from

1 the group? So just to remind everybody that the  
2 face validity only gets you to moderate under NQF  
3 rules, but if there's no more thoughts, I think  
4 we're ready to vote on validity.

5 Christine. Sorry.

6 MEMBER RITCHIE: So just a quick  
7 question about the removal of the exclusions. So  
8 my worry there is that if we remove the  
9 exclusions and we happen to have a hospice that's  
10 in a community that gets late referrals that this  
11 would be a potential disadvantage to them if they  
12 can't, if they're getting referral the day of,  
13 they will not be able to meet the measure.

14 And I just wondered, is there a plan  
15 to engage in a risk adjustment around that or how  
16 were you thinking about addressing that issue?

17 MS. HANSON: So the data's in the  
18 packet, but basically, very purposely, out of the  
19 HIS analysis for each of the measures where that  
20 seven-day exclusion had been utilized, the RTI  
21 analyst then provided a comparison to basically  
22 demonstrate that that does not preclude needing

1 the quality measure, that that is not as much of  
2 a threat to hospice practice as was assumed by  
3 the advisory panel when the measures were first  
4 specified with the seven-day exclusion.

5 And I have to say that there was a lot  
6 of back and forth about that initially in the  
7 PEACE measures because it would exclude so many  
8 hospice patients from being included in quality  
9 metrics. So we were relieved to see that the  
10 data didn't support that anxiety.

11 CHAIR MORRISON: Karl, last question.

12 MEMBER STEINBERG: Just wondering how  
13 difficult it would be to do 48 hours or 24 hours,  
14 you know, in relation to that concern.

15 MS. HANSON: So my RTI colleagues who  
16 are here can speak to that in even greater depth,  
17 but the reality is that we've been slicing the  
18 RTI data every way to Sunday and seeing basically  
19 that if you're going to meet this quality measure  
20 you're going to meet it through the initial  
21 assessment and management process.

22 CHAIR MORRISON: Everybody comfortable

1 to vote? Okay, back to Jean-Luc.

2 MR. TILLY: Great. So your options  
3 for voting on validity are high, moderate and  
4 low, and then insufficient number 4. Please go  
5 ahead.

6 Okay, the results are 1 high, 23  
7 moderate, zero low, zero insufficient. The  
8 measure passes.

9 CHAIR MORRISON: Okay, guys, we have  
10 three more to go. Feasibility.

11 MEMBER PURSLEY: Okay, feasibility,  
12 preliminary rating was moderate. The data is  
13 incorporated into the hospice medical record and  
14 it's transmitted directly to CMS.

15 So I think that the feasibility for  
16 hospice again is high. It's a standardized item  
17 set and it's easy to pull the data. I think for  
18 palliative, again that's a question.

19 CHAIR MORRISON: Ruth, anything to  
20 add?

21 MEMBER MACINTOSH: The NQF group rated  
22 it moderate and I'm in agreement with that.

1 CHAIR MORRISON: Terrific, thank you.  
2 Open for discussion. Okay, I think we can move  
3 to a vote then. Jean-Luc.

4 MR. TILLY: Okay, great. Your options  
5 for voting on feasibility are 1 high, 2 moderate,  
6 3 low, 4 insufficient.

7 CHAIR MORRISON: Rob, do you want to  
8 ask a question while we're waiting for the other  
9 three votes?

10 MEMBER SIDLOW: Sure. I'm sorry, this  
11 question might be a little late but it's a  
12 question about the actual specification. I was  
13 sort of digging in here and noticed that  
14 screening positive is anybody with a measure  
15 above zero on the dyspnea screening and that  
16 should trigger an intervention.

17 And just thinking practically,  
18 wouldn't a screen trigger be a little higher,  
19 like 4, because I wouldn't necessarily start an  
20 intervention at a 1, for example.

21 MS. HANSON: Welcome to my world. So  
22 a lot of debate back and forth about that

1 specific aspect of specification, I'm amazed no  
2 one else raised it so I'm glad you did.

3 And it is still an issue that's under  
4 active discussion in thinking about  
5 implementation of this quality measure and the  
6 one that we'll eventually discuss on pain  
7 assessment which relies on that same concept that  
8 you screen positive but at what level of  
9 severity?

10 The difficulty is that our advisory  
11 panel could not come to consensus that there was  
12 a clear-cut point that should be used for  
13 dyspnea, so we ended up with a concept that if  
14 the patient said they were short of breath, sort  
15 of going back to the basic concept of what is a  
16 symptom, if they said they were short of breath  
17 they were short of breath and it needed to be  
18 addressed.

19 It's important to recognize that  
20 treatment did not require administration of  
21 medication. Treatment could be any medication or  
22 non-medication based approach that addressed the

1 symptom of dyspnea.

2 But I do agree with you that it's a  
3 point that I have questions about as well. We  
4 used the specification that our advisors led us  
5 to use.

6 CHAIR MORRISON: Jean-Luc, can we have  
7 a final? And then I think Cindi has a comment, I  
8 know.

9 MR. TILLY: Actually we're missing one  
10 vote in the room, if you all could just try it  
11 just once more with the clicker. That's right,  
12 yes. Press as many times as you like.

13 MS. ROILAND: And remember to point it  
14 at Jean-Luc. Okay, we've got 24.

15 CHAIR MORRISON: Why don't we do that  
16 and then I'll take Cindi's question.

17 MR. TILLY: Very good. The results  
18 are 1 for high, 23 moderate, zero low, zero  
19 insufficient, and the measure passes.

20 CHAIR MORRISON: Cindi, you had a  
21 comment?

22 MEMBER PURSLEY: Yes, I just wanted to

1 say as a reminder that it's also the patient's  
2 decision as to whether or not their dyspnea needs  
3 treatment, because we may have patients that  
4 appear very dyspneic to us but they're very  
5 comfortable with it and prefer not to treat. So  
6 I just wanted to throw that out there.

7 CHAIR MORRISON: Yes. Let's move on  
8 to usability, last voting -- no, second to last  
9 voting.

10 MEMBER PURSLEY: Usability and use,  
11 these measures are not publicly reported. My  
12 understanding, it's going to be middle of 2017 at  
13 the earliest that these will be publicly  
14 reported.

15 Accountability use or planned use,  
16 it's very much a part of what hospitals are  
17 tracking as well as CMS, so I think that the  
18 usability and use, let's see, was moderate and  
19 that was the preliminary rating.

20 CHAIR MORRISON: Comments? Actually,  
21 I'm sorry. Ruth, anything to add? You were the  
22 other discussant.



1 CHAIR MORRISON: Nothing to add.

2 CHAIR MORRISON: Comments, thoughts?

3 Open to vote. Jean-Luc.

4 MR. TILLY: All right, voting is now  
5 open. Your options are 1 for high, 2 for  
6 moderate, 3 for low, and 4 for insufficient.

7 So we're looking for just three more  
8 votes in the room, so if you have some doubt  
9 about whether or not it went through just try  
10 pressing it again. That's exactly right. A  
11 light or a flashing number, really, is a signal  
12 that it succeeded.

13 CHAIR MORRISON: Make sure everybody  
14 points at Jean-Luc.

15 MR. TILLY: I think we need just one  
16 more, sorry. Okay, great. So the votes are 2  
17 for high, 22 for moderate, zero for low, and zero  
18 for insufficient information. The measure  
19 passes.

20 CHAIR MORRISON: So guys, the long  
21 primary season is over. We now move into the  
22 general election. This is where you get to vote

1 on up or down on endorsement or not.

2 MR. TILLY: All right, so for overall  
3 suitability for endorsement, there are just two  
4 options, one yes and two no.

5 MS. ROILAND: All right, we needed to  
6 meet that magic 24 number and we need one more in  
7 the room, so if you all could point again. Oh,  
8 are we -- oh, he's out of the room. Okay. All  
9 right.

10 MR. TILLY: Thanks very much for  
11 mentioning that. The results are 21 yes and 2  
12 no, so the measure passes.

13 CHAIR MORRISON: All right, guys, just  
14 before we break, we need a quick look at whether  
15 there are any competing measures and there's  
16 opportunity for the committee to talk either  
17 about competing measures or harmonization.

18 There are two potentially competing  
19 measures identified, but not really. I don't,  
20 you know, they're up there. One, you could see  
21 them if anybody has a comment about that.

22 Okay, so we're all done, folks. We

1 have 16 more hours if we continue this pace just  
2 on measures alone. Fortunately, Deborah's going  
3 to read us through things after the break, and  
4 she's a social worker and handles family meetings  
5 much better than I do.

6 So let us reconvene at five of 11. We  
7 will try and get ourselves back on track. And  
8 just a heads up, after this we're going to be  
9 moving much more quickly. This was deliberately  
10 slow to get everybody onboard.

11 (Whereupon, the above-entitled matter  
12 went off the record at 10:38 p.m. and resumed at  
13 10:55 a.m.)

14 MS. JOHNSON: Okay. We need to go  
15 ahead and get started again. So if you'll take  
16 your seats please, we'd appreciate it. We are  
17 running a little bit late now, but I think we can  
18 catch up with our timing. So, Deborah, I'll hand  
19 it to you.

20 CHAIR WALDROP: Okay. Welcome back,  
21 everybody. And first, I want to welcome Amy  
22 Berman. Thanks for joining us. And we need to

1 ask you to just briefly introduce yourself, and  
2 then state if you have any disclosures on the  
3 measures.

4 MEMBER BERMAN: Good morning,  
5 everyone. My name is Amy Berman. I'm a Senior  
6 Program Officer at the John A. Hartford  
7 Foundation in New York City, which is a roughly  
8 \$500 million dollar foundation focused on the  
9 improving the care of older adults.

10 A good portion of the work that we do  
11 is in the field of palliative care. I've been  
12 Diane Meyers' program officer, for example, for  
13 the past 11 years. We also tend to find many  
14 other things that go on in this field. So this  
15 is also, professionally, my background around  
16 improving quality of care for people who are  
17 seriously ill and at the end of life.

18 I also, five and a half years ago, was  
19 diagnosed with Stage 4 inflammatory breast  
20 cancer. The prognosis, 11 to 20 percent survive  
21 to five years. I'm a person who made choices and  
22 publicly speaks about them and writes about them.

1                   And because of those choices, I've  
2                   lived very well, very well. And I feel very  
3                   well, thanks to the work that many of you in the  
4                   room do. So I thank you all personally and  
5                   professionally for what you do.

6                   In the interest of disclosure, should  
7                   I continue into the disclosure piece? The only  
8                   disclosure that I have to report is that I was on  
9                   the ASCO Palliative Measures Panel. And that was  
10                  this past year.

11                  And the measures that we looked at  
12                  were 209, 210, 211, 213, 215, and 216. So on  
13                  those measures I will not be weighing in. I will  
14                  be recusing myself. And I will not be providing  
15                  comment. Thank you.

16                  CHAIR WALDROP: Okay. Thank you, Amy.  
17                  So now we will move into a little quicker pace  
18                  for the next several measures, for the next, rest  
19                  of the measures for today. But I have to ask  
20                  your forbearance. This is new for me. And so,  
21                  I'm going to just jump in, and hope that I can  
22                  keep the process moving, with the assistance of

1 Karen, Rachel, and Sean.

2 So, we're going to move on now to  
3 Measure Number 1639, which is a paired measure  
4 with the measure we've just previously reviewed.  
5 This is Dyspnea screening. And I'm going to turn  
6 to our discussants, and ask, I believe it's Ruth  
7 who will be starting with the evidence for us,  
8 please.

9 MEMBER MACINTOSH: Yes, thank you.  
10 This should move quicker since we spent the time  
11 last time. The evidence is, first of all, this  
12 is number 1639, Hospice and Palliative Care  
13 Dyspnea Screening.

14 The percentage of hospice or  
15 palliative care patients who are screened for  
16 dyspnea during the hospice admission evaluation  
17 or the palliative care initial encounter, it is  
18 the level analysis clinician, group practice, and  
19 facility.

20 It's not a new measure. It's a  
21 maintenance measure process. And the evidence is  
22 there from previous. And the developer presented

1 updates in evidence. So the evidence is there.  
2 I don't know if you need a vote.

3 CHAIR WALDROP: No, that's okay.  
4 Cindi, do you have anything that you'd like to  
5 add?

6 MEMBER PURSLEY: I agree.

7 CHAIR WALDROP: Okay. Discussion,  
8 questions, comments from the committee? No  
9 comments from the committee. Any comments from  
10 the committee?

11 MS. JOHNSON: So this is Karen. I'll  
12 step in here as staff. You'll note that in our  
13 preliminary analysis we had selected  
14 insufficient. And that is because that when we  
15 were reading this we felt that there was not  
16 strong evidence to show that screening actually  
17 improves outcomes.

18 So, I'd like to invite you to discuss  
19 this just a little bit. Is there additional data  
20 that might show this? Or, if not, I can talk  
21 about a pathway that we might could go down if  
22 you do feel that the evidence is actually

1 insufficient.

2 Again, we are looking for, in terms of  
3 evidence, we're looking for a link to show that  
4 screening improves outcomes. That's the link  
5 that we're looking for.

6 CHAIR WALDROP: Okay. So, comments on  
7 whether or not the evidence is sufficient on  
8 whether screening makes a difference in  
9 treatment? Thanks. Michelle.

10 MEMBER CAUGHEY: So, clearly there's  
11 not the evidence presented, nor am I aware of it  
12 in the literature. But I think this is a  
13 measure, like the pain measure, that should be  
14 considered by exception.

15 CHAIR WALDROP: Other thoughts?  
16 Comments?

17 MEMBER MACINTOSH: The developer did  
18 add two guidelines. And one was 2011 British  
19 Columbia Medical Services. That was based on a  
20 systematic review of the evidence. But the  
21 evidence wasn't graded.

22 I agree that this should be by



1 exception. We can't treat dyspnea without the  
2 screening. And we have a roads to go with the  
3 palliative care, as discussed before.

4 CHAIR WALDROP: Doug.

5 MEMBER NEE: I just concur with that  
6 last statement. Absolutely.

7 CHAIR WALDROP: Thank you.

8 MS. JOHNSON: So, let me explain how  
9 we would do this. If you agree that there isn't  
10 evidence showing that link, but you still feel  
11 that there might be room in the NQF portfolio to  
12 continue to endorse this, we now have what we  
13 call an exception to the evidence criterion.

14 And we talked about it here in the  
15 preliminary analysis, that if you look at your  
16 algorithm, and you guys have the algorithm there  
17 in front of you. I'd invite you to pull that  
18 out. And let's just walk through the algorithm  
19 very quickly, thank you, Marcia.

20 So, the first box, Box 1, asks if it's  
21 an outcome measure. And we know that it's not.  
22 It's a process measure. And in Box 3 we want to

1 know if it, the measure is based on a systematic  
2 review and grading of the body of evidence.

3 So, while there were systematic  
4 reviews included here, they were not graded. And  
5 we did not see a summary of what we call the  
6 quantity, quality, and consistency in the body of  
7 evidence. I think the boxes that were checked up  
8 there may have been checked erroneously.

9 That takes us to Box 7, is empirical  
10 evidence submitted, but without systematic review  
11 and grading of evidence? That's the idea that if  
12 there are articles, but there's been no  
13 systematic review, that's okay too, as long as  
14 you're pulling the whole body of evidence, okay.

15 But I don't believe that additional  
16 articles were submitted. So that takes us down  
17 to Box 10. And that's the path for evidence  
18 exception. So, basically, what this asks is, are  
19 there, or could there be performance measures of  
20 a related health outcome, or evidence based  
21 intermediate outcome or process?

22 And if the answer is yes, then we

1 would not want you to rate this as insufficient  
2 with the exception. However, if they're not,  
3 then you would go on over to Box 11 and ask if  
4 there's a system, if there's evidence of a  
5 systematic assessment of expert opinion.

6 Now, in this case -- and sorry, that  
7 the benefits of what is being measured outweigh  
8 the potential harms. In this case the answer  
9 would be yes, because you have the systematic  
10 reviews that just weren't graded, right.

11 And then finally, that would take you  
12 to Box 12. Do you, as the steering committee,  
13 agree that it is okay to hold providers  
14 accountable for performance in the absence of  
15 empirical evidence of benefits to patients?

16 And you would follow your thinking  
17 there. If you think it is okay then you would  
18 rate as insufficient evidence, but with an  
19 exception. Otherwise, you would rate as  
20 insufficient.

21 So, when we get to this voting, and I  
22 apologize, my glasses are not as good as I would

1 like. You have four options here. So, if you  
2 believe that you would like to go down the  
3 exception path, what we need for you to do is to  
4 vote insufficient on this voting activity right  
5 now.

6 Thank you, Jean-Luc, that helps. If  
7 more than 60 percent of you vote insufficient,  
8 then we will have a second vote as to whether we  
9 will actually invoke the evidence exception. And  
10 that'll be a yes or no, okay.

11 If you believe that what is here is  
12 actually sufficient information, then you would  
13 vote high, moderate, or low, okay. So you see  
14 the difference? It's a little tricky, so I want  
15 to make sure everybody's clear. Arif.

16 MEMBER KAMAL: I'm just going to  
17 submit here at the eleventh hour that I knew  
18 there was a paper. I'm just working to find it.

19 MS. JOHNSON: Okay.

20 MEMBER KAMAL: From a book chapter we  
21 wrote actually. The first author is Seow. It's  
22 from the Journal of Oncology Practice from 2012.

1 And what they show is that as documentation of  
2 both pain and dyspnea went up, clinical decisions  
3 to address that symptom went up in a dose  
4 response way.

5 MS. JOHNSON: Okay.

6 MEMBER KAMAL: And so they pointed out  
7 both for pain and shortness of breath. So as  
8 documentation went up from 37 percent to 71  
9 percent, dyspnea-related actions from the  
10 clinician went up from 4.2 percent to 37 percent.  
11 So, screening led to clinical action.

12 MS. JOHNSON: Okay. So that is a case  
13 where we actually have some additional evidence.  
14 And that's okay. Because you guys are the  
15 experts. And you would know this. So, you can  
16 certainly take that into account, what Arif has  
17 told us about. Any other questions about  
18 process? Go ahead.

19 MEMBER HANDZO: Yes. I would just ask  
20 then, help me out here on the algorithm. Run --  
21 assuming that we knew about that, and it was  
22 included in the evidence analysis, and the staff

1 knew that, where would that lead you in terms of  
2 a recommendation?

3 MS. JOHNSON: If it were there, and if  
4 it were summarized in a way that I could  
5 understand it, right, and if I also felt that  
6 that was pretty much the body of evidence. So  
7 that there's not other things out there that  
8 would show something different.

9 And I felt like the whole body of  
10 evidence is there, then I would probably say that  
11 I would probably land on, if I were doing it, I  
12 would probably land on moderate as opposed to  
13 low. If I thought that it wasn't the full body  
14 of evidence, then not so much. If I thought that  
15 there was conflicting evidence, I would land on  
16 low.

17 MEMBER NEE: So we're back to square  
18 one, based on what you just said.

19 CHAIR WALDROP: Okay. Okay. So, I  
20 didn't see the order of these. But I'll go with  
21 Gregg first.

22 MEMBER VANDEKIEFT: So, I'm curious

1 where that leaves us, since this is just brought  
2 up. You know, we haven't had a chance to review  
3 that evidence. And even, Arif, I'm not sure that  
4 documentation equals screening. So there's an  
5 inference there. How do we integrate that new  
6 information into our decision making today?

7 MS. JOHNSON: I'll take it, and kind  
8 of do the, my favorite answer at NQF. Is it  
9 depends. It really depends on how comfortable  
10 you are with making that choice. If you feel  
11 like that that isn't the link that you want to  
12 see, then you would vote accordingly.

13 If you feel like that is enough of a  
14 link to make you feel like that the screening  
15 would lead to better outcomes, then you could  
16 vote the other way.

17 I will say that if it turns out that  
18 we go a route other than exception, I would ask  
19 Laura to go back, and just add that information  
20 to the submission. So that it's very transparent  
21 that if you did land on something different,  
22 where that would come from.

1 CHAIR WALDROP: I think what I'm going  
2 to do is take the committee members first. And  
3 then I'll ask Laura -- offer Laura a chance to  
4 respond. So, Paul?

5 MEMBER TATUM: Mic has moved forward  
6 so you can hear me when I hit the button. To  
7 confirm, insufficient kills the process, but  
8 clarification about a low evidence, the process  
9 moves forward?

10 MS. JOHNSON: So, clarification. If  
11 a high majority, that is more than 60 percent of  
12 you, land on insufficient, it doesn't kill it  
13 yet. It would take it to the next question,  
14 which is, do you want to actually invoke the  
15 evidence exception? And we would have a vote on  
16 that as well.

17 MEMBER TATUM: My apologies. You were  
18 clear on that earlier, and I used the wrong  
19 terminology. But the low continues the process,  
20 correct?

21 MS. JOHNSON: If a majority land on  
22 low, the measure dies.



1 MEMBER TATUM: Got it.

2 MS. JOHNSON: So there is a very large  
3 difference between low, which would probably  
4 suggest conflicting data, something like that, as  
5 opposed to insufficient, which is, there's not  
6 enough to actually let me rank it one way or the  
7 other.

8 CHAIR WALDROP: Steve, and then  
9 Deborah, and Michelle. Deborah.

10 MEMBER WIEGAND: I just had one  
11 question about the article that you just  
12 reported. I'm sorry, I don't know his name.

13 MEMBER KAMAL: Arif.

14 MEMBER WIEGAND: Arif. Just a  
15 question about the article. What population --  
16 thank you.

17 CHAIR WALDROP: Michelle.

18 MEMBER CAUGHEY: While it's great that  
19 we have introduced the new article, and some new  
20 information, we don't know that that respects the  
21 process that we've all undertaken, which is to  
22 review what we had in great detail, particularly

1 those that were responsible for the measure.

2 And so, I would suggest that we take  
3 that under review for our next panel. And that I  
4 don't think it should be added into the  
5 discussion, my apologies to my colleague.

6 CHAIR WALDROP: Paul, your card is  
7 still up. Did you have another question?

8 MEMBER TATUM: Just pleased to  
9 announce that this is a great process. Thank  
10 you.

11 CHAIR WALDROP: I need to apologize to  
12 our developer, Laura Hanson, for not including  
13 you to begin with, but I'd like to give you the  
14 chance to address some of these questions.

15 MS. HANSON: No apology needed. I'm  
16 delighted to be skipped over. It's wonderful.  
17 And I feel like I introduced the pain screening  
18 measure because it's a paired measure with the, I  
19 mean, I'm sorry, the dyspnea screening measure,  
20 because it's a paired measure.

21 I mostly just wanted to comment back  
22 to your question, Gregg, that if the committee

1 decides, and there may be a procedural point  
2 here, to include the Seow reference, these  
3 process measures are based on documentation. So  
4 that's how they're, that's the body of evidence  
5 that screening actually occurred. So in that  
6 sense it would parallel the reference.

7 CHAIR WALDROP: With due respect for  
8 the -- oh, Deborah.

9 MEMBER WIEGAND: So just to ask a  
10 process question. I thought though if there was  
11 evidence that hadn't been presented, that we were  
12 supposed to bring it up in today's discussion.  
13 Is that not correct?

14 MS. JOHNSON: It becomes a little  
15 tricky. Because we want you in one way to look  
16 at what's in front of you, and vote that way.  
17 But we also know that you bring your own set of  
18 expertise. And you might know something in and  
19 of yourself, or your colleagues may tell you  
20 something that may change a little bit.

21 So all we can really advise is for you  
22 to take what you've heard, and do the best that

1       you can with what, how you understand our  
2       criteria.

3               CHAIR WALDROP:   Okay.   With due  
4       respect for the process, I'd like to move us  
5       along, unless there are any other comments to  
6       vote, to vote on the evidence.   Jean-Luc, let us  
7       know when you're ready.

8               MR. TILLY:   The polling is now open  
9       for a vote on evidence.   Your options are one  
10      high, two moderate, three low, and four  
11      insufficient.

12              (Pause.)

13              MS. ROILAND:   Amy, if you're on the  
14      phone, if you could text your vote to Jean-Luc,  
15      we'd appreciate it.   Thank you.

16              MEMBER SANDERS:   I'm trying.

17              MS. ROILAND:   Or if the chatbox is  
18      better, you can use that too, or email.

19              MR. TILLY:   The votes are zero for  
20      high, three for moderate, one for low, and 19 for  
21      insufficient.   So the verdict on evidence is  
22      insufficient.

1 CHAIR WALDROP: So then we move to a  
2 vote about the exception.

3 MS. JOHNSON: And let me add just here  
4 with this vote we actually need for this to carry  
5 greater than 60 percent. So, just so you know,  
6 the implications of your vote are.

7 If we, if more than 60 percent say  
8 insufficient evidence with exception, it will  
9 pass this criteria and we will continue. If not,  
10 there is no gray zone for this one. So if not,  
11 then it ends here.

12 MR. TILLY: So the vote for evidence  
13 on the potential exception to empirical evidence,  
14 your options, there are two options, one  
15 insufficient evidence with exception, and two no  
16 exception.

17 (Pause.)

18 MR. TILLY: The results are 22 for  
19 insufficient evidence with exception, and one for  
20 no exception. So the measure passes with  
21 insufficient evidence with exception.

22 CHAIR WALDROP: Okay. Thank you. So

1 we'll move into looking at gaps in care, and  
2 opportunities for improvement. These will  
3 address disparities in this section. And I'm  
4 going to go back to Ruth and ask if you would  
5 like to lead us through that?

6 MEMBER MACINTOSH: Yes. For the  
7 facility level for hospice we have quite a good  
8 data source from the same amount of the HQRP for  
9 2015. And we have high percentiles for the  
10 hospice. We don't have specific data, same thing  
11 for palliative care yet.

12 It was rated low opportunity for  
13 improvement, because most hospices are reporting  
14 on this measure. The performance seems to be  
15 tapped out. However, in disparities there is not  
16 as quite the high percentages there.

17 And again, this gets to low  
18 opportunity for improvement, but opportunity for  
19 both the disparities, and also the actual dyspnea  
20 treatment percentages we saw.

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

1 are ready --

2 (Off microphone comment.)

3 CHAIR WALDROP: Did you have a comment  
4 on the disparities, Christine? No? Okay.  
5 Seeing no further discussion, I believe we move  
6 to a vote on gaps in care. Jean-Luc?

7 MR. TILLY: Yes. The polling is open  
8 for the performance gap vote. Your options are  
9 one high, two moderate, three low, four  
10 insufficient.

11 (Pause.)

12 MR. TILLY: So the results are zero  
13 for high, 11 for moderate, 12 for low, zero for  
14 insufficient. So the measure is in the gray zone  
15 where consensus is not reached.

16 MS. JOHNSON: And just as a reminder,  
17 what that means is it did not pass this  
18 criterion. However, since it's in the gray zone,  
19 we will continue to discuss the measure.

20 CHAIR WALDROP: Okay. So we'll move  
21 on to reliability. And I just need to clarify,  
22 do we, we will vote on reliability and validity?

1 MS. JOHNSON: Yes, we will. This  
2 measure is quite similar to the one that we've  
3 just discussed. So the methods will be exactly  
4 the same I think. And all of your measures,  
5 Laura, right?

6 What will be different is the results.  
7 So, because the results are different, I would  
8 ask that you vote on this one after any  
9 discussion you may want to have.

10 And remember, for reliability it's not  
11 just the testing. So you're not just thinking  
12 about the testing results. You're also thinking  
13 in this portion of the discussion about the  
14 specifications. So if there's any questions or  
15 concerns you have about specifications, now would  
16 be the time to bring those forward.

17 CHAIR WALDROP: We start with Ruth,  
18 and ask if you have anything you want to add  
19 about the reliability and specifications.

20 MEMBER MACINTOSH: No. As Karen said,  
21 it was the same as last, as far as the actual  
22 testing. But for, with the results in the



1 facility level -- let me just look here.

2 The clinician, group practice level  
3 for palliative care, the single kappa value was  
4 0.91. So the raters agree 91 percent of the time  
5 over. And for facility level the split-half  
6 analysis was .83.

7 The developers reported a signal to  
8 noise ratio of 0.98, with one being the highest.  
9 The group for NQF rated the guidance from using  
10 the reliability algorithm for the facility level  
11 as high, and the clinician level using that  
12 algorithm as moderate.

13 CHAIR WALDROP: Thank you. Any  
14 comments from the committee? Laura? You had  
15 your thing up.

16 MS. HANSON: Oh, I apologize.

17 CHAIR WALDROP: Oh, okay. No worries.  
18 No worries. Okay.

19 (Off microphone comment.)

20 CHAIR WALDROP: Seeing no other  
21 indication of discussion, I think we're ready to  
22 vote on reliability of this measure.

1 MR. TILLY: The polls are open for  
2 voting on reliability. Yes, this is a new vote.  
3 Please hit one for high, two for moderate, three  
4 for low, and four for insufficient.

5 All right. We're missing actually  
6 just one vote in the room. So I'm sorry to make  
7 you keep doing this. But if you could try just  
8 one last time. Pointing it over here. Thank  
9 you.

10 All right. So the results for  
11 reliability are, four high, 19 moderate, zero  
12 low, zero insufficient. The measure passes  
13 reliability.

14 CHAIR WALDROP: Thank you. We'll move  
15 on to validity testing. And I'll go back to Ruth  
16 and ask if you have anything you'd like to add.

17 MEMBER MACINTOSH: I think the group,  
18 the developer noted that the specification was  
19 consistent with the evidence. The face validity  
20 is the same as what we discussed before for the  
21 palliative care. Same with the construct  
22 validity.

1           For hospice, they used the full year  
2    '15 data for almost 4,000 hospice organizations.  
3    And the validity testing results were,  
4    correlation results were positive and  
5    statistically significant for the facility level.

6           But they did find the magnitude of  
7    correlation was lower than expected. And that,  
8    the developer states the reasons for this may be  
9    due to clustering of scores, skew distributions,  
10   and low score variability.

11           Split out for the palliative care, the  
12   face validity indicated broad endorsement of the  
13   face validity of the measure from the stakeholder  
14   group. And the, it was felt that the exclusion  
15   was in there.

16           And we discussed that last time for  
17   removing the previous length of stay. We've got  
18   the assurance that when it was less than seven  
19   days it didn't greatly impact. So the  
20   exclusion's consistent with the evidence.

21           And the meaningful differences, the  
22   development -- developers examined 95 percent

1 confidence intervals to determine the proportion  
2 of hospices with results significantly different  
3 from the hospice level mean. And it indicated  
4 that 36.7 percent of hospices had a quality  
5 measure score that was significantly different  
6 from the national mean.

7 There was a low rate of missing-ness.  
8 And so, using the guidance from the validity  
9 algorithm, this was rated as moderate for both.

10 CHAIR WALDROP: Okay. Thank you. Any  
11 comments, or questions, or thoughts from the  
12 committee? I think we'll move to vote on  
13 validity of this measure.

14 MR. TILLY: All right ,the polling is  
15 now open to vote on validity. Your options are  
16 one high, two moderate, three low, four  
17 insufficient. All right. The results are two  
18 for high, 21 for moderate, zero for low, and zero  
19 for insufficient. The measure passes on  
20 validity.

21 CHAIR WALDROP: Okay, thank you.  
22 We'll move on to considering feasibility. And I

1 realize I've been leaving Cindi out. So I should  
2 turn to Ruth and Cindi, and ask if either of you  
3 have thoughts about -- like -- share about the  
4 feasibility of the measure.

5 MEMBER MACINTOSH: No. We consider it  
6 feasible. The group rated it as moderate,  
7 because we have the electronic health records for  
8 the hospice. And we realize that there can be a  
9 substantial collection effort for the palliative  
10 domain.

11 CHAIR WALDROP: Okay. Thank you. Any  
12 comments, thoughts? My understanding from Karen,  
13 if I can articulate this correctly, is that  
14 because of the similarity of our vote last time,  
15 we can decide to just carry over the vote from  
16 our, the last measure.

17 Can I see the thoughts of the  
18 committee? I see a thumbs up. I see a couple of  
19 thumbs up. Maybe you can explain it better  
20 anyway.

21 MS. JOHNSON: Sure. The question for  
22 you is, is the feasibility for this measure any

1 different in your mind than the feasibility of  
2 the last measure that we had?

3 If not, if there's nothing new, we  
4 will allow you to carry over votes from the last  
5 time. If anybody objects to that, we will have  
6 an actual vote, but --

7 CHAIR WALDROP: So, let me just ask if  
8 there's anyone who objects to carrying over the  
9 vote? Okay. Then I don't know what the process  
10 is. But we just apply the same number of votes  
11 to this measure. Okay. Which moves us on to  
12 usability and use of Measure 1639. And --

13 MEMBER MACINTOSH: This is not, it's  
14 the same as last. It's not currently used for  
15 public reporting for the hospice. It is used in  
16 the accountability program. It's the exact same  
17 as last time, if we're allowed to carry over the  
18 vote from that.

19 CHAIR WALDROP: Let me first ask if  
20 there are any comments about usability and use on  
21 this measure? And then I will invoke the same  
22 statement, which is that we can carry over our

1 vote, unless there's any significant difference  
2 that anyone notes between this and the previous  
3 measure.

4 Does anyone object to carrying over  
5 the vote? That said, brings us to the end of  
6 Measure 1639. We will look at competing  
7 measures?

8 MS. JOHNSON: No. We do need to do an  
9 overall vote for suitability.

10 CHAIR WALDROP: I'm sorry. We do need  
11 to do an overall vote for suitability of this  
12 measure. So, Jean-Luc, when you're ready, let us  
13 know.

14 MR. TILLY: Yes. So we're voting for  
15 overall suitability --

16 CHAIR WALDROP: So, we have a question  
17 before we vote. Sorry.

18 MEMBER RITCHIE: Just, again, as a  
19 point of clarification. So we didn't receive  
20 consensus on one of the measures, I mean, one of  
21 the criteria. How does that influence this  
22 overall voting?

1 CHAIR WALDROP: Good question. I'm  
2 going to ask Karen if you can clarify that for  
3 us?

4 MS. JOHNSON: So, this is where you  
5 really get to weigh individually how much you  
6 weight that one vote in yours specifically. So,  
7 if you voted low on reliability, that might be  
8 enough for you to not want to vote suitable for  
9 endorsement at all. And you would vote that way.

10 But you may say that in balance of  
11 what we know about evidence, what we know about  
12 gap, et cetera, you would still let that go  
13 through. And you could vote yes for overall  
14 suitability. So, it really is how you balance  
15 all the criteria going forward.

16 And I'll stop there and see if Elisa  
17 or Marcia had any other -- maybe you can put it  
18 in a little bit different way? Yes,  
19 clarification, Elisa.

20 We had consensus not reached on, was  
21 it reliability? Do we remember? I think it was.  
22 If they vote, and they vote something other than



1 consensus not reached --

2 CHAIR WALDROP: Gray zone was gap,  
3 sorry.

4 MS. JOHNSON: Gap, okay.

5 CHAIR WALDROP: It's gap. Yes.

6 MS. JOHNSON: Sorry. My mistake. It  
7 was gap.

8 MEMBER RITCHIE: And the reason I  
9 think that's important is because it raises an  
10 important question that will be a question that  
11 we keep asking, as a question some of us were  
12 discussing over the break, which is, how high is  
13 topping off?

14 And is there a topping off for a  
15 measure that's considered to be a basic,  
16 fundamental aspect of service and care? So  
17 that's just a question that I had to bring to the  
18 group.

19 MS. MUNTHALI: So, because you didn't  
20 reach consensus on a major sub-criterion, we will  
21 hold the overall suitability vote until the post  
22 comment call.

1 MS. WILSON: And if I could speak to  
2 topped out measures, This is an issue that comes  
3 up in every single committee. So this is a  
4 familiar conversation. Often, how high is high?  
5 The committee has to decide that.

6 But I think one of the larger issues  
7 is, if we declare a measure topped out, and it  
8 were eligible for reserve status, which you heard  
9 Karen explain earlier, does that mean we stop  
10 paying attention to it?

11 And that's often at the crux of the  
12 debate, is if a measure is topped out, and it  
13 goes to a reserve status, will people stop paying  
14 attention? And often the conversation falls into  
15 two camps, which is, we don't want it to go to  
16 reserve status, because we're afraid people will  
17 ignore it.

18 And at the same time there's that  
19 balance that's if it's topped out, should we be,  
20 should not us, NQF, the royal we, should we be  
21 requiring providers still to report it? So, it's  
22 a challenging issue, but it comes up in every

1 committee.

2 CHAIR WALDROP: And we're not voting  
3 at this point? We'll wait until the post --

4 MS. MUNTHALI: Yes. You're not going  
5 to vote. What we're going to do is wait for the  
6 public and member comments to come in, and see if  
7 that helps to move you one way or the other on  
8 the areas in which you weren't able to reach  
9 consensus. And then you take a final vote then.

10 CHAIR WALDROP: Thank you.

11 MS. JOHNSON: So, apologies for  
12 leading you wrong on that one

13 CHAIR WALDROP: So, does that conclude  
14 this measure?

15 MS. JOHNSON: So that concludes this  
16 measure. So, Laura, you're off the hot seat for  
17 now.

18 CHAIR WALDROP: Thanks, everybody. So  
19 that moves us on to consider 0209. but I just  
20 want to remind us that we have four measures and  
21 a discussion about related and competing pain  
22 measures to consider before lunch. So, I'm going

1 to try to move us a little faster. Okay. So,  
2 0209.

3 Okay. So, Doug and Debra are our  
4 discussants for 2000-0209. But I think I'd first  
5 like to start with asking our developers if you  
6 could just introduce this measure for us briefly.

7 MS. SPENCE: Thank you. So, let me  
8 start with introducing ourselves first. I'm  
9 Carol Spence. I'm Vice President for Research  
10 and Quality at the National Hospice and  
11 Palliative Care Organization. This is my  
12 colleague. Carl, do you want to introduce  
13 yourself?

14 MR. SCHEFFEY: My name is Carl  
15 Scheffey.

16 CHAIR WALDROP: Make sure your mic's  
17 on.

18 MR. SCHEFFEY: Ah, okay. My name is  
19 Carl Scheffey. I'm the Director of Analytics at  
20 NHPCO.

21 MS. SPENCE: Okay. So very, very  
22 brief introduction to this measure. As Laura

1 did, I'm going to just tell you a little bit  
2 about its origins. It goes all the way back to  
3 1998 when NHPCO convened, along with other  
4 organizations, something we call the Outcomes  
5 Forum.

6 Based on then, back then if you all  
7 remember Pathways? Well, we had developed a  
8 pathway for end of life care. And based on that  
9 pathway, were created by this Outcomes Forum  
10 three what we called outcome measures. But they  
11 were at the, you know, sort of up here at the  
12 20,000 foot level.

13 And so part of that then became, look,  
14 there's three outcome measures for effective  
15 breathing, self-determined life closure, and safe  
16 and comfortable dying. So there's where that  
17 comfortable dying piece comes in with this  
18 measure.

19 There's been a little confusion this  
20 measure was meant to encompass all of comfortable  
21 dying. And that is not true. Because this  
22 particular measure was what then was called an

1 instrumental measure.

2 In other words, one piece of that  
3 comfortable dying picture, which the comfortable  
4 dying was actually termed an end result outcome  
5 measure. And this was one instrumental measure  
6 in support of that. So that has been a little  
7 bit of a point of confusion, you know, along the  
8 way.

9 So, this, again, this measure was  
10 developed as an outcome measure, patient report  
11 outcome measure, as you know. The data are  
12 collected in two phases.

13 Initially on admission to hospice  
14 patients are asked a yes/no question, are you  
15 uncomfortable because of pain? And for those  
16 patients who answer yes, that they are  
17 uncomfortable, they then go into the measure.

18 And then on follow-up within, between  
19 48 and 72 hours there is a check back with those  
20 patients to ask if their pain was then brought to  
21 a comfortable level. So those two pieces of data  
22 collection are what constitute then the, this is

1 where you get the numerator and the denominator,  
2 you know, for the measure.

3 I want to say a little bit about the  
4 benefits of this measure. It is the patient's  
5 voice. You know, you go on to, once those  
6 questions are asked, then the clinician, the  
7 hospice clinician goes on to do their full  
8 assessment with whatever assessment tool is  
9 appropriate for that patient.

10 So, you know, as you probably know,  
11 pain is subjective. So, for example, on a zero  
12 to ten scale, one person's two could be another  
13 person's seven. This measure allows for the  
14 patient to simply say, indicate are they  
15 comfortable, or are they not comfortable.

16 It doesn't presuppose or impose  
17 anybody else's, including the clinician's  
18 judgment on what level of pain, when you're  
19 looking at intensity, or anything else, you know,  
20 needs to be achieved, you know, for that patient.  
21 And I think that is one of the primary benefits,  
22 you know, of this measure.

1 CHAIR WALDROP: Thank you.

2 MS. SPENCE: So that, I'm just, yes,  
3 I think that's pretty much. I can also, again, a  
4 little bit about, a little more about history or  
5 not. But just very quickly, I think again one  
6 possible point of confusion is, so this measure  
7 is, has had NQF approval, and was one of the  
8 measures that CMS chose to implement for hospices  
9 during that very first year of quality reporting  
10 that was required, you know, for hospices.

11 CMS then chose, after not even a full  
12 year of data collection, to drop the measure, and  
13 move on to the process measures that are now in  
14 HIS.

15 I would think about, I would also want  
16 to give you a little bit of a context for that,  
17 so that you understand some of what was going on  
18 in the hospice community. And perhaps, part of  
19 the decision making on CMS's part reflected this.

20 Hospice was one of the three provider  
21 types that was pinpointed in the ACA legislation  
22 to institute a hospice quality reporting program.



1 Because we did not have one before that. Hospice  
2 is coming very, very late to the table in terms  
3 of looking at quality.

4 Again, this measure was put in place  
5 back in 1998. But there wasn't even a conditions  
6 of participation requirement for a quality  
7 assessment performance improvement program for  
8 hospices to have their own until 2006.

9 So, hospice's thinking, the individual  
10 provider's thinking about quality, what  
11 constitutes a quality measure, what's a  
12 numerator, what's a denominator, I fully admit  
13 that my hospice community was rather far behind,  
14 you know, the times in that.

15 So this was the first pre-specified  
16 measure that hospice has had to implement, unless  
17 they were voluntarily using this measure. And  
18 being a patient self report it meant data  
19 collection in a way that they were not accustomed  
20 to. And it was tough going, you know, to be  
21 absolutely honest about it.

22 And also, it was the first time that

1 they had to put together a system for collecting  
2 data that they then had to turn around and submit  
3 to, you know, to CMS. So that, in and of itself,  
4 was a huge step for hospices.

5 So I would say this measure, you know,  
6 had challenges to start with. I would've really  
7 liked to have seen it given, left in place a  
8 little bit longer. Although I do understand  
9 CMS's decision.

10 Also though, it was my understanding  
11 from CMS that they at some point were interested  
12 in revisiting this measure, and working with us  
13 as the developers to perhaps, you know, see  
14 whether we could, you know, modify it or do some  
15 other things to make it, you know, get it back  
16 out there with hospices. Okay.

17 CHAIR WALDROP: Thank you for the  
18 context. So I'm going to turn to Doug and Debra.  
19 I don't know if you would like to take the  
20 primary discussant role. Okay.

21 MEMBER NEE: Sure. I'll do that.  
22 Okay, so as far as evidence goes, essentially

1 pain is subjective. The evidence stands. There  
2 was new evidence that was provided. It really  
3 was an article out of the Oncology Nursing Forum  
4 in 2002.

5 Just, investigating the symptoms of  
6 distress and quality of life in with patients  
7 with cancer, and newly admitted to hospice care,  
8 did find a strong relationship between pain and  
9 distress. At this point in time, I don't really  
10 see much need for re-discussion or repeat voting.

11 CHAIR WALDROP: Thank you. Comments  
12 from the committee? Consideration of the context  
13 and of the statement that we don't maybe need to  
14 reconsider evidence. Paul. And then --

15 MEMBER TATUM: I would like to speak  
16 to the opportunity to modify this going forward.

17 CHAIR WALDROP: Okay.

18 MEMBER TATUM: And I'll provide  
19 anecdote from one hospice regional number, as  
20 opposed to national numbers. I think it's a  
21 great measurement. I think we need this  
22 measurement. My concern is that I think it ought

1 to be everyone in the denominator. And I'll give  
2 an anecdote.

3 In one month's QAPI meeting, only 9.8  
4 percent answered they had pain and got included  
5 in the measure. Yet 96 percent of the admitted  
6 patients had an opioid.

7 Because, in the Midwest, maybe  
8 somebody coming to your home you're being  
9 socially polite and saying, no, I'm fine.  
10 Thanks. Or maybe they knew a nurse was coming,  
11 and they planned ahead and took the pain medicine  
12 before they arrived.

13 And so, when the question was asked,  
14 at this moment are you uncomfortable? You're  
15 uncomfortable. So, just as you move forward, I'd  
16 like to encourage making that measurement all  
17 hospice patients on admission.

18 CHAIR WALDROP: Thank you. My  
19 understanding is we're not able to redo  
20 specifications of a measure at this point.

21 MEMBER TATUM: Oh. I just heard her  
22 comment that was an invitation from the future.

1 So I apologize if that was inappropriate.

2 CHAIR WALDROP: No. Do you want to  
3 comment on that? Okay.

4 CHAIR MORRISON: Just a comment that,  
5 if we're going to get through the day, we're not  
6 going to be able to really focus, drill down on  
7 the specs of the measure and redoing the measure  
8 that's presented.

9 MS. SPENCE: No. If I could just  
10 respond? Because I think I can clarify a little  
11 bit. That again, this measure was meant to focus  
12 on those patients, not who had their pain managed  
13 or, you know, or had pain. But who were  
14 uncomfortable on admission.

15 Therefore, it was an impetus to get  
16 busy for the hospice, and address that. It, you  
17 know, so it is very possible -- so the person who  
18 says, no, I don't have pain on that initial  
19 assessment, doesn't mean that you don't, that you  
20 ignore the fact that they're on opioids, et  
21 cetera.

22 It's just you don't, it's the

1 addressing the person who is in pain, was  
2 intentionally the focus of the measure. With the  
3 understanding not everybody who was on pain  
4 medication was going to be uncomfortable on  
5 admission. So --. Absolutely.

6 CHAIR WALDROP: Thank you for the  
7 clarification. Cindi.

8 MEMBER PURSLEY: I am also addressing  
9 this from a user standpoint. When you ask  
10 patients if they have pain they frequently have  
11 arthritis. They have neuropathic pain from their  
12 diabetes. They have pain from their cancer.

13 And you may be able to manage that  
14 cancer pain, which is why you have them on  
15 hospice. And yet, when you ask them at 48 hours  
16 if their pain is under control they may say that,  
17 well, no, my joints still hurt.

18 So it's, you're not generally  
19 addressing just a pain in a place. And so, it  
20 does make it a little bit difficult sometimes to  
21 utilize this question in a way that's meaningful.

22 CHAIR WALDROP: Okay. Thank you.

1                   MEMBER KAMAL: I'm just going to  
2 really quickly say, so, you know, in palliative  
3 care we don't have a lot of outcome measures. So  
4 it's important that, you know, as a field we sort  
5 of keep an eye towards maintaining the few that  
6 we have.

7                   From a policy perspective we, you  
8 know, we really can't participate in  
9 reimbursement mechanisms, in Part A or Part B,  
10 without having outcome measure as part of our  
11 overall cohorts. I think we should keep an eye  
12 towards that.

13                  Because there's not many that we're  
14 going to review today. So, I know from an NQF  
15 assessment perspective, outcome measures are, you  
16 know, reviewed at a higher level, which they  
17 should be.

18                  I think from a clinical content  
19 expertise, and us looking out for the discipline  
20 perspective, we should also keep a high bar to  
21 try to keep at least one or two within the field,  
22 for all the reasons I said.

1 CHAIR WALDROP: Okay. Cindi? More?  
2 Oh, sorry. Okay. Other thoughts, other  
3 comments? Are we ready to vote on the evidence?  
4 Jean-Luc?

5 MR. TILLY: So you're voting for  
6 evidence and here this is a health outcome.  
7 There are just two options, one for yes, and it  
8 passes, two for no, does not pass. I think we're  
9 missing just one more response in the room, if  
10 you all want to try again.

11 CHAIR MORRISON: Let's everybody --

12 CHAIR WALDROP: Can everyone try --

13 CHAIR MORRISON: -- re-vote one more  
14 time.

15 MEMBER BERMAN: As a reminder I'm a  
16 recusal.

17 MEMBER SANDERS: Wait, what was that  
18 last? Did you guys have to re-vote?

19 MS. ROILAND: No, that's fine, Amy.  
20 We're fine. Thank you, though.

21 MR. TILLY: Okay, great. Thanks to  
22 everyone for voting. The, we received 21 votes



1 in support of, yes, and one for no. So the  
2 measure passes on the evidence.

3 CHAIR WALDROP: Thank you. So we'll  
4 move on to considering gaps in care and  
5 opportunities for improvement, and also  
6 disparities. And I'll turn it back to Doug.

7 MEMBER NEE: Okay, terrific. So the  
8 description of performance data was presented  
9 over four years, from 2012 to 2015. Essentially  
10 the distribution of scores was reasonably  
11 consistent over that time period. And the range  
12 of means was between 61.4 and 66.4.

13 Standard deviation was a range of 20  
14 to 24. Essentially, deciles of the facility  
15 scores in 2015 for 50 percentile. The score was  
16 65 percent or less for this measure. And 65  
17 percent or less of the hospices did score at this  
18 rate.

19 There really didn't seem to be,  
20 although there's no current established cutoff,  
21 but it really didn't seem to be any topping out  
22 of this measure as well. Disparity data was

1 looked at for race, ethnicity, gender, age,  
2 insurance status, and so forth.

3 Initial testing data included six  
4 months, a total of 1,409 patients. They looked  
5 at 463, or 30 percent, of patients who responded  
6 uncomfortable for pain.

7 The results showed that relative to  
8 cancer versus non-cancer pain, that the comfort  
9 level was 81 percent verse 84.8 percent  
10 respectively. No disparities there. No  
11 statistical significance was identified. But the  
12 percentages were pretty close.

13 No statistical significance was  
14 identified for ethnic distribution of patients  
15 whose pain was brought under control, versus not  
16 brought under control.

17 Further analysis in 2014 showed no  
18 statistical significance for a sample disparity  
19 relative to age, gender, or race. So the  
20 disparities appear to support the usability of  
21 the measure.

22 CHAIR WALDROP: Great. Thank you.

1 Anything to add, Debra? Okay. Comments or  
2 thoughts from the committee on gaps,  
3 opportunities for change? Okay. Seeing none I  
4 think we're ready to go ahead and vote on gap,  
5 and the performance gap. Jean-Luc.

6 MR. TILLY: This is for -- the polling  
7 is now open to vote on the performance gap. Your  
8 options are one high, two moderate, three low,  
9 and four insufficient.

10 Okay. So the polling is now closed.  
11 We received 16 votes for high and seven for  
12 moderate, zero for low, and zero for  
13 insufficient. So the measure passes the  
14 performance gap.

15 CHAIR WALDROP: Okay, thank you.  
16 We'll move on to reliability and validity. Debra  
17 or Doug?

18 MEMBER NEE: Yes. So, as far as  
19 reliability goes, just looking at numerator and  
20 denominator, exclusions as well. Data source is  
21 patient's self report of pain. There were really  
22 no issues or concerns regarding specifics in the

1 measure.

2           There was a little, there was a  
3 discussion actually on our workgroup call,  
4 relative to language barriers. And it was kind  
5 of thought that, maybe if there was an  
6 interpreter, or same interpreter asking the  
7 question, whether you had pain, and then asking  
8 the question afterwards, 48 hours later, if you  
9 achieved comfort, would be something that would  
10 be very helpful.

11           The initial testing, I'm going to,  
12 okay, so I'm going to qualify here. There was  
13 updated testing that was provided. And I'm going  
14 to let Dr. Scheffey talk about that.

15           But first, I thought I would just  
16 interject that the initial testing looked at 58  
17 hospices and 38,000 patients, analyzed between  
18 2009 and 2010.

19           The developer utilized inter-class  
20 correlation coefficient, and examined the agency  
21 level between, versus within variances of the  
22 measure, using the two years of data. Just

1 quickly looking at statistical significance that  
2 was set at .05.

3 People reporting being uncomfortable  
4 due to pain remain relatively constant. As  
5 expected, there were significant differences in  
6 the percent of hospices reporting patients  
7 uncomfortable due to pain on admission, verse  
8 within the hospice.

9 Indicated the ICC demonstrated over 75  
10 percent consistency of results within hospices  
11 from quarter to quarter. There was a follow-up  
12 testing looking at, again, between and within  
13 hospice variation was found to be .71. A value  
14 of .7 is often regarded as minimum acceptable  
15 reliability value.

16 So that was initially the initial  
17 testing, and follow-up, relative to statistics.  
18 And if, there was a follow-up, updated testing  
19 done by NHPCO. But I thought I'd have Dr.  
20 Scheffey discuss that.

21 CHAIR WALDROP: Did you want to  
22 comment?

1 (Off microphone comment.)

2 MEMBER NEE: Sure. And that's great.

3 MR. SCHEFFEY: On the subject of  
4 reliability, I'll add a few comments about the  
5 data that's come in since the initial submission.  
6 We did get very much more data during the period  
7 2012 through 2015.

8 I included in the, in this submission,  
9 information about stability, and some stability  
10 considerations. The stability is quite good. It  
11 -- that's the score -- that's, that addresses the  
12 question of score-level reliability.

13 On the individual-level reliability  
14 there was -- we stand on the data that was  
15 provided with the initial submission, which was  
16 an experiment on 236 patients. It was 96 percent  
17 agreement on how the patients reported their  
18 subjective impression of pain. I think that says  
19 enough right there. A top out of .91 is very  
20 good.

21 On the score level reliability, in  
22 spite of my comments about stabilities in the

1 scores, the NQF staff did complain about how,  
2 well, if he shows stability over time, that is  
3 not the whole story for reliability.

4 I point out, first, with this measure,  
5 there are limits to what you can do. But  
6 actually, we did mention a result that is  
7 effectively a split sample validation, a split  
8 sample of my ability.

9 I, this, NQF has accepted, sometimes,  
10 split sample work that's based on just random  
11 reassignment of patients within a hospice. And  
12 in our submission, in Section 2A2.3, we give a  
13 result about how close the score would come if we  
14 ran the test again and just supposed that we had  
15 a random new sample of patients.

16 That is, and we state, if the score  
17 was 58 percent to begin with, then we'd have an  
18 80 percent chance of being between 48 percent and  
19 68 percent.

20 That result, which we reported on the  
21 subject of reliability, is identical to the  
22 result you'd get if you were looking at a split

1 sample validation on a hospice with 100 patients  
2 in the denominator. So that is our evidence on  
3 reliability.

4 CHAIR WALDROP: Thank you very much  
5 for clarifying. Comments from the committee?  
6 Questions? Okay. Seeing none, I think we're  
7 ready to vote on reliability.

8 MR. TILLY: So, polling is now open to  
9 vote on reliability. Your options are, one high,  
10 two moderate, three low, and four insufficient.  
11 So the results are three for high, 18 for  
12 moderate, two for low, and zero for insufficient.  
13 So the measure passes reliability.

14 CHAIR WALDROP: Thank you. So we'll  
15 move on to validity. Will that be --

16 MEMBER NEE: Okay, so for validity,  
17 the developers compared response rates from two  
18 different wordings, comfortable level and  
19 acceptable level, with a follow-up question  
20 related to pain.

21 No new testing was, or testing data  
22 was not provided. However, it appears new



1 statistical data on the initial testing was  
2 provided in support of validity for the measure.

3 The initial test measure of score  
4 level included 212 of 686 patients from nine  
5 different hospice agencies. In response, 66  
6 responded comfortable, 64 percent responded  
7 acceptable.

8 And I'll back up just for a second.  
9 So, when they were asked the question, they're  
10 asked these questions sequentially I'm presuming,  
11 correct? Yes, as I read it. Was your pain  
12 brought to a comfortable level? Was your pain  
13 brought to an acceptable level?

14 Just looking at these two responses,  
15 96 percent of patients gave the, a same answer in  
16 total, kind of indicating good concurrent  
17 criterion validity for the measure.

18 Updating tests, updated testing looked  
19 at kappa values. And a kappa value of .91 was  
20 actually reached. Confidence intervals were not  
21 necessarily reported. But that was the kappa  
22 level that was identified, indicated a high level

1 of agreement between the two responses.

2 As far as threats to validity, there  
3 really was no identifiable threats to validity,  
4 no risk for the measures that was cited.

5 Standard care for hospice is to provide timely  
6 and effective pain management, based on patient  
7 preference.

8 No exclusions. The patients were  
9 identified, are examined, measured. Exclusion  
10 criteria did not have any glaring, as far as I  
11 could see, groups inappropriately excluded from  
12 the measure.

13 Regarding meaningful differences in  
14 performance, they looked at 97 hospices, with  
15 greater than 50 patients in the denominator and  
16 found 16 per-- 16 hospices, or actually five  
17 percent, as statistically significant measure  
18 scores on the national average, with 292 hospices  
19 reporting.

20 I don't know, essentially, what that  
21 means relative to meaningful differences from a  
22 clinician's standpoint, looking at statistics

1       verse clinical effectiveness.

2               The developer indicated that samples  
3       used had very little missing data.  However there  
4       was -- NQF identified that there was a failure to  
5       provide that data on frequency of missing data.

6               The only other thing that I had as a  
7       side note is it's -- one might argue, and it's  
8       not to deter anything here.  But as far as  
9       acceptable and comfortable, sometimes we have  
10      patients that say their pain is acceptable, but  
11      they're really not comfortable.  So I don't know  
12      if that really plays into here, but I just wanted  
13      to throw that in there.

14              NQF recommendations on this one were  
15      insufficient, I believe.  Is that correct?  Yes.

16              CHAIR WALDROP:  Thank you.  Any  
17      comments from the committee on sort of the  
18      concept of words matter?  Is it acceptable?  Is  
19      it comfortable?  Any thoughts about that, or  
20      Doug's comments on missing this?  Cindi?

21              MEMBER PURSLEY:  I do want to come  
22      back to the perception from patients, and the way

1 we were able to improve our scores, because  
2 that's what we were looking at, we had to  
3 identify at admission, what is your most  
4 uncomfortable pain? Okay. So it's a knee. All  
5 right. And that's what we have to evaluate at 48  
6 hours.

7 Because all of our patients have many  
8 other illnesses, many co-morbidities that result  
9 in discomfort. And so we had to narrow it down  
10 to one specific pain.

11 Because you can manage some and not  
12 others quite as well. And so, I think that that  
13 did create some issues. And that may be part of  
14 the differences in statistical outcomes.

15 CHAIR WALDROP: Okay. Thank you.  
16 Sean.

17 CHAIR MORRISON: I just had a question  
18 as to why there is no risk adjustment given the  
19 number of years this has been out there and the  
20 data points that you have. And why it hasn't  
21 been risk adjusted as an outcome measure.

22 MS. SPENCE: Well, on the basic

1 demographic information, there were no  
2 differences. So there was no basis there to risk  
3 adjust. What would you like to see it risk  
4 adjusted on?

5 CHAIR MORRISON: I'd like to see a  
6 couple of things. I think increasingly we are  
7 seeing too many differences in socioeconomic  
8 status. I think certainly we are seeing  
9 differences in -- regional differences. And so I  
10 have difficulty, and certainly within diagnosis,  
11 but the over and under 65 risk adjustment,  
12 without differences, doesn't seem to me --

13 MS. SPENCE: We did look at age.

14 CHAIR MORRISON: Yes. I said over and  
15 under 65.

16 MS. SPENCE: Yes, yes. Right.

17 CHAIR MORRISON: But the others I  
18 would certainly like to have seen, particularly,  
19 and perhaps co-morbidities.

20 CHAIR WALDROP: Cindi? Oh, other  
21 questions, comments? Cleanne?

22 MEMBER CASS: Yes. I have a little

1 concern about the comfort. Would it be better if  
2 the numerator were patients who had their pain  
3 reduced by two points or three points or  
4 something rather than bringing them down to  
5 completely comfortable? Is that safe and  
6 appropriate in 48 hours?

7 MS. SPENCE: So I understand your  
8 reasoning behind that. But it goes back to my  
9 point I was making when I was talking about it,  
10 that when you start putting clinician judgment in  
11 there or setting an arbitrary whatever, then you  
12 take that patient's voice out of it.

13 And the point of this measure was to  
14 have the patient define comfort for them. And  
15 when you start trying to then impose the  
16 assessment scales --

17 The other thing is that not everybody  
18 can use 0 to 10. You've got other's different  
19 assessment scales thrown in there: mild,  
20 moderate, severe; in some cases you're using  
21 faces. Because the clinician will adapt their  
22 assessment instrument to the needs and the

1       abilities of the patient.

2                   CHAIR WALDROP:   Yes.

3                   MS. SPENCE:   So because of that lack  
4       of uniformity of an assessment instrument across  
5       the board we chose to use comfort.  We also did -  
6       - but I agree with you.  It is a high bar.  But  
7       we chose that on purpose.

8                   The other thing, though, to keep in  
9       mind though, is that 100 percent should never,  
10      will never be the set threshold for this measure.  
11      There's types of pain that you cannot get under  
12      control within that 48 hour window.

13                   You know, neuropathic pain is  
14      difficult.  If the pain is existential in nature  
15      and being expressed physically, you're not going  
16      to be able to even figure that out and get it  
17      addressed in 48.  So that is understood that that  
18      is not your goal.

19                   And also, when you've got pain from multiple  
20      sources, you're also probably, and depending on  
21      the severity, depending on the long standing  
22      nature of it, you're probably not going to get

1 that all done in 48 hours.

2 So that part is maybe, perhaps wasn't  
3 explicit in the submission materials. But it  
4 certainly is part of the understanding behind the  
5 measure.

6 MEMBER CASS: Yes. And that would  
7 probably have to do with the acceptable  
8 percentile in the scores --

9 MS. SPENCE: Exactly.

10 MEMBER CASS: -- at some point. But  
11 as we're increasingly using methadone as well and  
12 bringing people into the inpatient unit, we know  
13 that they're going to get better over a few days.  
14 But it's going to be more gradual.

15 And our clinicians have a hard time  
16 with this criterion. They feel like they could  
17 put patients in jeopardy if they were expected to  
18 get them completely comfortable.

19 MS. SPENCE: And exactly -- yes. And  
20 so again, you know, there were no thresholds set.  
21 We didn't get to that point with it. But they  
22 absolutely would not be at 100 percent. Nor



1       should hospices.

2                   And, I mean, and that would be made  
3       clear also, that we're not encouraging overdosing  
4       patients with pain medication with this measure.

5                   CHAIR WALDROP:   Thank you for the  
6       clarification.   Amy.

7                   MEMBER BERMAN:   I apologize.   I was  
8       recused from an ASCO measure, not your measure.  
9       So I'm participating.   So, I have a question.  
10      What are the implications, for example, of a  
11      patient that might have been a drug abuser,  
12      somebody who is not medication naive?

13                   Are there exceptions, exclusions to  
14      this kind of a measure?   Are there things that  
15      you have to consider?

16                   And the other comment kind of goes to  
17      Cindi's comment.   And you're making such  
18      brilliant comments.   But as a human being on the  
19      receiving end of care, I don't want somebody to  
20      look at a body part; I want them to look at me  
21      overall.

22                   The notion of pain is kind of an

1 absolute. Am I uncomfortable, or am I  
2 comfortable? And this distinction in whether or  
3 not the pain has been resolved, the acceptable  
4 component is I think closer to what is likely  
5 true.

6 There are tradeoffs. And there may be  
7 tradeoffs. But is it an acceptable level for  
8 that patient is probably closer to right from a  
9 human being perspective.

10 MS. SPENCE: So, Amy, to your point,  
11 both of your points of that patient who says,  
12 yes, I'm uncomfortable, but I'm going to refuse  
13 pain medication because of my history with  
14 addiction or whatever reason.

15 And also, that patient who, maybe they  
16 have multiple sources of pain, making it complex  
17 to treat them, that also goes back to where you  
18 would set the threshold.

19 So in neither of those cases would the  
20 expectation be that that patient be brought to a  
21 comfortable level within the 48 hours.

22 So those patients, they wouldn't be

1 considered exceptions because we're not exempting  
2 them from the measure. But there's where you go  
3 to, looking at that.

4 Perhaps, Sean, even risk adjusting on  
5 the proportion of those patients. Risk adjusting  
6 on things like short length of stay for those  
7 patients that can't re-self report at that second  
8 follow-up, which is also an issue. And that came  
9 out. Both of those things came out in the  
10 reporting.

11 So just one note of clarification.  
12 The measure itself, the question is, are you  
13 comfortable? The acceptable word was put in the  
14 validity testing, with the idea that while the  
15 two --- and I agree with you, Doug, that they're  
16 not necessarily comparable. But if the -- what  
17 we were looking at was, would the patient's  
18 response change if that -- with that word  
19 acceptable? And the answer came back, no. So  
20 therefore, they showed that they were comparable.

21 We had questions going in. Would they  
22 turn out to be comparable? They did turn out to

1 be that. But semantically, yes, we recognize  
2 there's a difference there.

3 And we went with comfortable, again,  
4 with the idea of, if that set the bar higher,  
5 that's what we wanted. But it turned out that it  
6 did not with the testing.

7 CHAIR WALDROP: So, I'm going to thank  
8 you for your clarification, move -- take one more  
9 comment, and move us to a vote to keep us on  
10 track with time here. So, Cindi.

11 MEMBER PURSLEY: To Amy's point, and  
12 also the developer's. If questions like these  
13 are yes or no, it doesn't take in for the  
14 variations that the vast majority of hospice  
15 patients, that's where they lie.

16 They're not going to be, you know, if  
17 you ask most hospice patients, are you  
18 uncomfortable because of pain? Yes. Was your  
19 pain brought to a tolerable level within 48  
20 hours? Again, it comes back to, if it's no, that  
21 is a score that that hospice is held to.

22 And we want to be able to show that we

1 are doing the very best for our patients. And  
2 those questions don't always allow that to shine  
3 through.

4 CHAIR WALDROP: Thank you. I'm going  
5 to move us towards voting on validity, but first  
6 I just want to ask Karen to say brief word about  
7 the insufficient assessment by the staff.

8 MS. JOHNSON: So, why did we land on  
9 insufficient? Really just a couple of things.  
10 And one I don't think we've hit. Although, I  
11 believe we talked about it in the workgroup call.

12 You didn't talk about exclusions. And  
13 I think it might be just a miscommunication in  
14 the submission about what is an exclusion. Maybe  
15 some people aren't -- maybe you can just speak to  
16 that in a minute.

17 The other thing that we noticed is, we  
18 were curious, as Sean asked, about the risk  
19 adjustment. And you do have some information  
20 about not seeing differences in those factors.

21 Our question was, did you report  
22 patient level data? Or did you report agency-

1 level data. Because if it's uniform across  
2 agencies, then we would agree that risk  
3 adjustment class probably isn't needed. But it  
4 looked like it was patient-level data that was  
5 shown. So, I think that was the question there.

6 And that doesn't necessarily address  
7 all the things that you could have looked at.  
8 And we didn't get into that. And let's see, I'm  
9 looking, is there anything else?

10 The final comment, additional score  
11 level validity testing may also be needed.  
12 That's only if you don't really accept that doing  
13 the comfortable versus acceptable is a valid  
14 demonstration of validity.

15 To be honest with you, we had two or  
16 three of us look at it internally. And one said,  
17 yes, it was. The other said I don't think it is.  
18 So we put it out there for you. This is for you  
19 to decide if that is an okay check to validity.

20 CHAIR WALDROP: Thank you for that.  
21 Did you want to comment?

22 MS. SPENCE: First, let me just start

1 by saying I think we -- this should be there  
2 somewhere in the submission, but just to clarify.  
3 Between 46 to 48 percent of patients say they  
4 have no pain on admission. So it's not the  
5 majority who are saying that they have pain.

6 I'm going to ask -- well, in terms of  
7 the exclusions, you're right. On our call it  
8 came up. It's a little bit of semantics going on  
9 here. Again, as the measure is in two parts, our  
10 exclusions are sort of in two parts. You can  
11 call the first one defining the sample, if you  
12 want to.

13 So the people who are not considered  
14 for the measure are those who are under 18, where  
15 there's no way for them to understand the  
16 question because of a language problem, and using  
17 both interpreters, including family interpreters,  
18 is fine. And this came out in the implementation  
19 when CMS had it implemented. We made that clear.

20 And then the patients who cannot self  
21 report, and either they can't self report because  
22 of their underlying disease makes them

1 cognitively unable to report, or they're so ill  
2 that the cannot self report.

3 So that group is not considered for  
4 the measure to start with. In a purer sense, the  
5 exclusion are those people who say they're not  
6 comfortable, I mean they are comfortable. So  
7 therefore they're not uncomfortable. Therefore,  
8 that's the true exclusion group for the measure.  
9 And we did look at those.

10 CHAIR WALDROP: Thank you.

11 MS. SPENCE: And was there one more,  
12 Karen, about the risk?

13 MS. JOHNSON: Yes, the risk factors.  
14 Was that patient-level data that you showed, or  
15 was that agency-level data?

16 MR. SCHEFFEY: Okay, sorry. The data  
17 we reported was patient-level. We have a little  
18 bit of facility-level data we could use for that.  
19 We could pursue it more in the future if we got  
20 more data in, had more power, yes.

21 CHAIR WALDROP: Okay, I think we need  
22 to move towards voting on validity of Measure



1 0209.

2 MEMBER STEINBERG: Just one quick  
3 question. I'd just be curious to know what the  
4 discussants and you guys on the work group  
5 thought of it. I mean, to me it seems more kind  
6 of like moderate. So I'm just -- anything?

7 MEMBER NEE: We really didn't have a  
8 whole lot to discuss on the work group call  
9 relevant to comfortable, acceptable, that sort of  
10 thing. For what appears to be a really simple  
11 measure, there sure is a whole of passion, and  
12 concern, and angst associated with it.

13 So just from a clinician standpoint,  
14 looking at this, it really is tough. And what  
15 other words would you look at? And looking at  
16 the exclusion data we had, as Carol had  
17 mentioned, we did have some conversation about  
18 that, and what could or couldn't, and what  
19 constitutes -- you know, voting age of 18 versus  
20 how low do you go in age as far as things like  
21 that occur. But, yes, we didn't have too much  
22 more than that.

1 CHAIR WALDROP: Thank you. And I  
2 believe Alice on the phone has a question for us.  
3 Alice?

4 MEMBER LIND: I sort of lost track of  
5 when you were going through the exclusions. Did  
6 you mean that people who use family members to  
7 translate for them are included as long as you  
8 get a translated answer to the question?

9 CHAIR WALDROP: I'm getting a yes from  
10 Carol. You can't see her nod her head, but I  
11 can. Okay. I think that brings us to a vote on  
12 validity. Jean-Luc?

13 MR. TILLY: So, yes, polling is open  
14 to vote on validity. Your options are one: high;  
15 two: moderate; three for low; and four for  
16 insufficient.

17 CHAIR WALDROP: So perhaps you can  
18 interpret for us.

19 MR. TILLY: Yes. So the results are  
20 one high, eight moderate, six low, and eight  
21 insufficient, which is a consensus not reached.

22 MS. JOHNSON: Let's do our math here.

1 We've got one plus eight is nine out of 23.

2 MR. TILLY: Right.

3 MS. JOHNSON: We want to be careful.

4 I'm seeing that as 39.

5 MR. TILLY: Yes, you're right. Yes --

6 -

7 MS. JOHNSON: So at this point, it  
8 actually did not pass validity. Because it has  
9 to be 40 to 60 inclusive to get that.

10 I think what we can do, because there  
11 was a lot of insufficient. A lot of people felt  
12 that there wasn't enough information here. Let's  
13 find out what you'd like to see. This is not the  
14 end of the game, necessarily.

15 We will be having a post-comment call.  
16 And we could potentially look at some extra  
17 information if it's something that you could pull  
18 for us, Carol.

19 I'm thinking one of the things might  
20 be the agency-level age distribution to indicate  
21 risk adjustment potential. I'm not sure if there  
22 are others. Maybe we can just have the committee

1 first tell us why you landed on insufficient.  
2 What would you like to see to get you out of  
3 insufficient? We'll find out if that's possible  
4 for Carol to do.

5 CHAIR WALDROP: Christine?

6 MEMBER RITCHIE: I think more data  
7 around or a plan to risk adjustment.

8 CHAIR WALDROP: Woody?

9 MEMBER MOSS: I was concerned about  
10 the 16 out of the 97 hospices where we didn't  
11 have a very good feel on what was going on and  
12 why they fell out of the target. So I had  
13 concerns about the data there.

14 CHAIR WALDROP: Other suggestions for  
15 how to make the data less -- or more sufficient?

16 MS. JOHNSON: Do you think this is  
17 something you have about six weeks or so before  
18 this next fall is ---

19 MS. SPENCE: So the thing is is that  
20 when we do our national data collection, we  
21 collect aggregated data. The patient-level data  
22 that we had, we did as a concerted effort to ask

1 for patient-level data from several hospices so  
2 we would have that. Because it's not part of or  
3 normal data collection.

4 I don't that in -- so age is not  
5 something, for example, that we had it from those  
6 hospices, which is why we did it at patient-  
7 level. We don't have a lot of hospices that we  
8 have that level of data.

9 So I don't that within six we'd be  
10 able to get it. We can try. But I can't  
11 guarantee that we'd be able to.

12 So I just want to be clear. Is the  
13 focus here mostly risk assessment? Because I  
14 want to able for us to focus our --- I could  
15 certainly come up with a plan for risk  
16 assessment.

17 Because I have ideas for risk  
18 assessment that go beyond your regular just  
19 demographic, that I think are really more germane  
20 to this measure in terms of digging down and  
21 really showing where the meaningful differences  
22 are. If a plan -- I can certainly present a

1 plan.

2 CHAIR WALDROP: Sean, then Paul, then  
3 Amy.

4 CHAIR MORRISON: Yes. I'm not sure.  
5 I think what I'm hearing, Carol, when I hear it,  
6 is that there's, and the committee can correct  
7 me, I think there are some concerns about the  
8 risk adjustment. I'm not sure that people are  
9 specifically asking for a risk adjusted model.  
10 But I think at least some interagency data would  
11 be helpful. And I'm not sure that would be too  
12 difficult for you guys to provide. Is that fair?

13 MR. SCHEFFEY: Well, the trouble with  
14 that is many of our hospices are very mixed in  
15 their populations. It's not as though I can say,  
16 ah, here I have five hospices that have purely  
17 urban populations and low SES.

18 MS. SPENCE: But we can, I mean, we  
19 can look at it, Sean, and see what we can do.

20 (Off microphone comment.)

21 MS. SPENCE: Yes, right. So we can at  
22 least tell you what we were able to do.

1 CHAIR WALDROP: Paul?

2 MEMBER TATUM: I was just going to  
3 argue for at least regional adjustments.

4 CHAIR WALDROP: Yes, Amy.

5 MEMBER BERMAN: Just a process  
6 clarification. So when I see these numbers here,  
7 so 9 would have been 4 out of 15 if we were to  
8 look at the insufficient as a separate, whether  
9 we wanted an exception or non-exception. Am I  
10 misunderstanding?

11 MS. SPENCE: Just a little bit.  
12 Exception only counts for evidence. So we don't  
13 have an exception for validity like we did for  
14 evidence. So basically, what we're looking at is  
15 high and moderate, is that enough to get you to  
16 at least that 40 percent mark or not? And the  
17 math got us at 39 percent.

18 But we'll talk with Carol offline.  
19 We'll see what's possible. Again, we can revisit  
20 at post-comment. It might be that you have the  
21 data, and you can allay fears of, or fears is the  
22 wrong word, but concerns about risk adjustment.

1 And that would be fair.

2 CHAIR WALDROP: Process clarification,  
3 do we vote on feasibility, or do we stop?

4 MS. JOHNSON: Let's go ahead and stop.  
5 We are a little bit along the way in our time.  
6 So let's stop. If they bring stuff back to us at  
7 post-comment, and it makes it past the validity  
8 hurdle, at that point we'll talk about  
9 feasibility and usability and use.

10 CHAIR WALDROP: So that concludes our  
11 discussion of 0209. Just being process-oriented,  
12 it's 12:25. We have stopped with three more  
13 measures by now. Do we just keep going?

14 (No response.)

15 CHAIR WALDROP: Okay. So we'll keep  
16 on going. We'll move on to Measure 1634.

17 MEMBER MOSS: Deborah?

18 CHAIR WALDROP: Yes? Sorry, Woody.

19 MEMBER MOSS: So I'm just wondering  
20 about process. At this rate, we're going to be  
21 here until sometime next week. Sean brought that  
22 up in his introductory remarks.



1 I was thinking we would have  
2 supposedly scanned these things at least in  
3 advance. And we should be pretty snappy in our  
4 responses and questions and moving right through  
5 them. Karen, is that unfounded, or is that what  
6 most of your groups do?

7 MS. JOHNSON: It depends. My favorite  
8 answer. Some things go a lot faster than others.  
9 Some groups never go fast. Others go really  
10 fast. We laugh about the surgeons, how fast they  
11 go through things. And the endocrinologists  
12 don't. So it kind of depends.

13 CHAIR WALDROP: So maybe we can try  
14 just stepping it up a bit and seeing if we can  
15 get through next couple in a shorter period of  
16 time.

17 CHAIR MORRISON: As Laura brings up,  
18 I think, Woody, you raised a good point. I think  
19 there are a couple of things that help. One is  
20 to be ahead of and be prepared with your comments  
21 about what you want to run through them.

22 The second is really to speak to data

1 and not anecdote. And the third, as we talked  
2 about at the beginning, people can get very  
3 emotional about these. And if a point's been  
4 made, it doesn't need to be repeated. Otherwise,  
5 I mean, Doug and are completely comfortable being  
6 here until as long as it takes. We like hanging  
7 out with you guys.

8 CHAIR WALDROP: Okay. So I'd like to  
9 welcome Laura Hanson back and ask you to give us  
10 a very brief overview of 1634, pain screening.

11 MS. HANSON: I'm so terrified. I'm  
12 between you and lunch. But very briefly, the  
13 pain screening piece measure is very similar to  
14 the Dyspnea screening measure that you recently  
15 reviewed and is basically also submitted as a  
16 paired measure.

17 So it's paired with pain assessment in  
18 that the results from a pain screening measure  
19 define the denominator population for individuals  
20 who should have a pain assessment.

21 Also, similar to what you've heard  
22 before for this measure, we're submitting data to

1 remove the exclusion for hospice -- individuals  
2 enrolled in hospice who have been enrolled less  
3 than seven days. And I'll stop there.

4 CHAIR WALDROP: Thank you very much.  
5 So I'll move it to our discussants who are Bob  
6 Archuleta and Michelle Caughey. And if you could  
7 please give us an overview of the evidence.

8 MEMBER CAUGHEY: I would like to say  
9 I think we can go fairly quickly on these two  
10 measures. They are paired. I wanted to thank  
11 the committee, the subcommittee. They were very,  
12 very helpful. And you've been exceedingly  
13 helpful on discussion. I'd like to move to the  
14 punch line, which is insufficient evidence with a  
15 recommendation for evidence -- or exception.

16 CHAIR WALDROP: So any more about that  
17 suggestion?

18 MEMBER CAUGHEY: Well, I think that,  
19 you know, there's general agreement by every  
20 clinician that assessing for pain is extremely  
21 important.

22 CHAIR WALDROP: Okay. Comments from

1 the committee, thoughts about this?

2 MS. JOHNSON: So just to be sure, this  
3 would be like the other one. If you feel like  
4 there is insufficient evidence linking screening  
5 to better outcomes, then you would vote  
6 insufficient as we did before. If more than 60  
7 percent of you vote insufficient, then we have  
8 the option of thinking about going the exception  
9 route.

10 CHAIR WALDROP: Christine?

11 MEMBER RITCHIE: This is a quick  
12 reminder that the paper we've mentioned looked at  
13 both pain and dyspnea. Thank you.

14 CHAIR WALDROP: Any other comments,  
15 thoughts about this measure? Seeing none, I  
16 believe we are ready to vote on the evidence.  
17 Just want to remind you that if we vote  
18 insufficient then we will be -- if a significant  
19 number of us vote insufficient, then there will  
20 be the following vote to consider an exception.

21 MR. TILLY: That's right, yes. So the  
22 polling is now open evidence. Please vote 1 for

1 high, 2 for moderate, 3 for low, and 4 for  
2 insufficient.

3 The results are 2 for high, 2 for  
4 moderate, 0 for low, and 19 for insufficient. So  
5 the measure goes insufficient.

6 So the vote is now open for evidence  
7 of -- a potential exception to critical evidence.  
8 Here we have just two options. 1 for  
9 insufficient evidence with exception, and 2 for  
10 no exception.

11 So the vote is unanimous. 23 voted 1,  
12 insufficient exception --- insufficient evidence  
13 with exception. And none voted for no exception.

14 CHAIR WALDROP: Okay, thank you. So  
15 I'd like to move on now to look at gaps and  
16 opportunities for improvement. Michelle?

17 MEMBER CAUGHEY: Yes, thank you.  
18 There are clearly opportunities for improvement  
19 among hospices in doing this, which surprised me.  
20 So there is definitely a moderate opportunity.

21 There were, interestingly, no  
22 disparities identified in the 1b measure. So I

1 think the preliminary rating of moderate is  
2 appropriate. I think there are opportunities for  
3 improvement.

4 I will mention and remind you that we  
5 have good data for hospice and that we will be  
6 having data for palliative care. So I'm only  
7 reporting palliative care because we've already  
8 had that discussion, unless others want to have  
9 that discussion.

10 CHAIR WALDROP: Okay, Christine? Did  
11 you have a question? I'm sorry, okay. I just had  
12 to make sure. Comments or questions on gaps and  
13 opportunities for improvement with this measure?  
14 Now we're rolling here. Okay. So I'd like to  
15 move us then to consider a vote for gaps and  
16 opportunities for improvement.

17 MR. TILLY: The polling is now open  
18 for the performance gap. Please vote 1 for high,  
19 2 for moderate, 3 for low, and 4 for  
20 insufficient.

21 The results are 1 for high, 19 for  
22 moderate, 2 for low, 1 for insufficient. The

1 measure passes for performance gap.

2 CHAIR WALDROP: Thank you. So we'll  
3 move on to consider reliability and the  
4 specifications. Michelle?

5 MEMBER CAUGHEY: For reliability, I  
6 agree with the assessment of moderate  
7 reliability. You'll recall that, again, for the  
8 hospice item set that there are a large number of  
9 hospices reporting with very large numbers of  
10 patients. And so it is a reliable measure in the  
11 hospice item set.

12 And inter-rater reliability is also  
13 moderately high. For palliative care, there's  
14 some information about inter-rater reliability as  
15 well but in a small number of patients.

16 CHAIR WALDROP: Okay. Should I just  
17 ask if Bob is on the line? Anything else to add,  
18 Bob?

19 MEMBER ARCHULETA: No, other than I  
20 think the percentage of reporting by hospices was  
21 in the range of 82 to 100 percent. So obviously  
22 it was very high reliability.

1 CHAIR WALDROP: Great. Thank you.  
2 Any comments or questions or thoughts from the  
3 committee? Okay. Seeing none, I'd like to move  
4 us to a vote on reliability.

5 MR. TILLY: Yes. The poll is now open  
6 for reliability. Please vote 1 for high, 2 for  
7 moderate, 3 for low, and 4 for insufficient.

8 The results are 5 voting for high, 18  
9 voting for moderate, 0 voting for low, and 0  
10 voting for insufficient. The measure passes on  
11 reliability.

12 CHAIR WALDROP: Okay, thank you. So  
13 that moves us into the area of validity, validity  
14 testing, and any threats to validity. And I'll  
15 go back to Michelle and/or Bob, whoever was going  
16 to take this position.

17 MEMBER CAUGHEY: Bob knows more about  
18 statistics than I do. Please chime in.

19 MEMBER ARCHULETA: I'm good with your  
20 discussing it, since ---

21 (Laughter.)

22 MEMBER ARCHULETA: -- you know the



1 committee's take.

2 MEMBER CAUGHEY: Well, definitely our  
3 subcommittee agreed with the rating for moderate  
4 validity.

5 So there was some missing data, but it  
6 was very, very small. What else should I say  
7 about validity, which I don't completely  
8 understand from a statistical point of view? I  
9 never did, and I'll ask Karen if you have  
10 anything to add.

11 MS. JOHNSON: Again, just when you're  
12 thinking about testing specifically, you think  
13 about the scope of the sample that was used in  
14 the testing. You think about the method. The  
15 methods were appropriate. And then you look at  
16 the results. And we did try to put the results  
17 and develop our thinking as well, try to put  
18 those into some kind of context for you.

19 CHAIR WALDROP: Thanks. Any threats  
20 to the validity that you saw of significance?

21 MEMBER CAUGHEY: Again, only in the  
22 palliative care realm and not in the hospice

1 realm.

2 CHAIR WALDROP: Okay. Thanks. Seeing  
3 no further comments from the committee, I'd like  
4 to move us to a vote for validity on 1634.

5 MR. TILLY: And the polling is now  
6 open for validity. Please vote 1 for high, 2 for  
7 moderate, 3 for low, and 4 for insufficient.

8 The results are 1 voting high, 22  
9 moderate, 0 for low, and 0 for insufficient. So  
10 the measure passes validity.

11 CHAIR WALDROP: Okay. So I'm learning  
12 that we can consider feasibility and usability in  
13 use through the same lens that we considered the  
14 dyspnea measure some hours ago. We've still got  
15 to open --- I want to open that just to see if  
16 there are any objections, since the methods are  
17 the same. I'm wondering if there's any  
18 objections to using the vote that we captured  
19 earlier. Any problems with it?

20 (No response.)

21 CHAIR WALDROP: Okay. Then we will  
22 cut and paste that vote and move on to the next -

1 - to the overall measure, the overall vote of  
2 acceptability of this measure. So when you're  
3 ready, Jean-Luc, let us know.

4 MEMBER RITCHIE: Is it possible to  
5 review what we just said? Can you review for us,  
6 please, just review the votes?

7 MR. TILLY: Yes. So on evidence, we  
8 voted insufficient with exception. Oh, sure,  
9 sure.

10 MS. JOHNSON: Let's clarify,  
11 Christine. Did you want to know the votes for  
12 this measure so that we can do the overall?  
13 Okay. So carry on, Jean.

14 MR. TILLY: Very good. All right.  
15 So, yes, we voted first insufficient, and then we  
16 passed it with insufficient evidence with  
17 exception. And we passed it on performance gap,  
18 1 high, 19 moderate, 2 low, 1 insufficient. On  
19 reliability, 5 high, 18 moderate.

20 CHAIR WALDROP: Okay. So let's move  
21 to the overall vote of acceptability of this  
22 measure.

1 MR. TILLY: Okay, the polling is now  
2 open for overall suitability for endorsement.  
3 Please select 1 for yes or 2 for no.

4 The vote is unanimous. 23 vote yes;  
5 0 vote no. The measure passes.

6 CHAIR WALDROP: So the measure passes.  
7 Thank you. So we'll move on to the assessment of  
8 -- the pain assessment measure, 1637. I'd like  
9 to begin by asking Laura if she has anything  
10 further she wants to add about this particular  
11 measure.

12 MS. HANSON: Just very briefly that  
13 this measure draws its denominator from the one  
14 that you just voted on. So for individuals who  
15 expressed pain at the time of initial  
16 comprehensive assessment in hospice or in  
17 palliative care, then the numerator condition  
18 here is to include at least five of seven  
19 elements of a comprehensive pain assessment in  
20 order to pass this quality measure. And  
21 likewise, this is one where we're looking for  
22 removal of the seven day exception.

1 CHAIR WALDROP: Thank you. And we'll  
2 stay with our discussants, Bob and Michelle. So  
3 I'll go back to you, Michelle.

4 MEMBER CAUGHEY: This is 1637. And  
5 the votes -- or what I would recommend is  
6 parallel to what we just went through which is  
7 the evidence is insufficient for the same reason.  
8 But the committee recommended, or we recommended  
9 an exception to that, that the quality of pain as  
10 described by the patient is extremely important  
11 to the clinician and to the patient, and that we  
12 recommend it be kept as a measure.

13 CHAIR WALDROP: Okay. Any comments or  
14 thoughts or concerns from the committee?

15 MS. JOHNSON: I have a note to myself  
16 that we had some additional evidence provided to  
17 us after the work group call. Is that what you  
18 were going to remind us of? So maybe you can  
19 just briefly describe what that was.

20 MS. HANSON: So just briefly, because  
21 there was concern about the evidence link with  
22 outcomes, I should give Kathryn Wessell the

1 credit, my colleague, my esteemed colleague who  
2 helps and works so vigorously on this project.

3 We basically looked for additional  
4 information, and I believe the attachment was  
5 offered to you, and basically found an additional  
6 systematic review as well as a couple of other  
7 individual publications that link systematic pain  
8 assessment, specifically with some patient-level  
9 outcomes: shorter length of stay in the ICU, less  
10 time on mechanical ventilation, decreased pain  
11 intensity, and decreases in adverse health  
12 events. So a modest body of evidence, but  
13 additional to what we had submitted.

14 CHAIR WALDROP: Thank you. And that  
15 was short turnaround. So we appreciate your  
16 supplying that additional information. Does that  
17 raise any questions or comments from the  
18 committee that we need to hear? Looks like we  
19 have one here.

20 MEMBER MOSS: So, yes, so is that  
21 tangential evidence, or is that just a little bit  
22 more evidence, but it's not enough to persuade us

1       that there's insufficient evidence?

2                   MS. HANSON: It depends. I think  
3       that's the answer. I think what is actually  
4       important about the additional evidence that we  
5       submitted, although it is limited primarily to  
6       the critical illness population, it is an  
7       interesting link between pretty compelling  
8       patient outcomes and assessing pain in a routine  
9       manner. So it depends.

10                  CHAIR WALDROP: Other -- Michelle.

11                  MEMBER CAUGHEY: Well, thank you. But  
12       I think, you know, it was in a limited setting.  
13       And we're recommending a measure across many  
14       settings. And so I think that is interesting.  
15       But that didn't change my thinking.

16                  CHAIR WALDROP: Okay. Seeing no other  
17       comments, I believe we move towards vote on the  
18       evidence for measure 1637.

19                  MR. TILLY: So for evidence, your  
20       options are 1: high, 2: moderate, 3: low, and 4:  
21       insufficient.

22                  Okay. And the results were 1 high, 9

1 voting moderate, 0 voting low, and 13 voting  
2 insufficient. So I believe the measure does not  
3 pass.

4 MS. JOHNSON: You are correct. We  
5 have to have more than 60 percent on insufficient  
6 for this to go through. And the percentages came  
7 out to 56.5 percent. So in this case, I think  
8 the additional evidence kind of split our vote a  
9 little bit there. So right now, it has died on  
10 evidence. Yes, it did not pass evidence.

11 PARTICIPANT: And no exception?

12 MS. JOHNSON: We could not get to  
13 exception.

14 MEMBER STEINBERG: Is it ever possible  
15 to re-vote?

16 MEMBER HANDZO: Karen, I didn't hear  
17 the end of your last comment. It kind of trailed  
18 off.

19 MS. JOHNSON: Oh, sorry about that.  
20 Yes, it did not pass evidence with this vote.

21 CHAIR WALDROP: Can I just ask, I  
22 think there is some confusion about whether the



1 exception is just for evidence or all others.

2 And I'm wondering, to pick up on your point, if  
3 we could, if it's possible to have a re-vote for  
4 people with the clear stipulation that only with  
5 evidence can we get to an exception. Is that  
6 correct?

7 MS. JOHNSON: Right. So what you have  
8 to ask yourself with the additional evidence that  
9 was provided is is that enough to get you over  
10 the hump. And by enough, it has to be -- you  
11 have to feel like that's the full body of  
12 evidence that would link in your mind assessment  
13 of pain to outcomes.

14 CHAIR WALDROP: Okay.

15 MS. JOHNSON: Again, we have to have  
16 more than 60 percent to get to insufficient. If  
17 we get there, then you can go on to potential  
18 exception.

19 CHAIR WALDROP: It's only possible to  
20 do this with the evidence vote.

21 MS. JOHNSON: Yes, right. So this is  
22 not something that's possible for reliability or

1 validity.

2 CHAIR WALDROP: Yes.

3 MEMBER MOSS: So can I read the first  
4 sentence of what Laura has sent us that's the  
5 updated evidence summary, if that's all right?

6 The first sentence says, "While there  
7 were no new high quality systematic reviews  
8 linking pain assessment to improved patient  
9 outcomes, we were able to find some additional  
10 evidence to support the measure."

11 And then when you go down and look,  
12 some of them are not the world's best class  
13 journals, BioMed Research International and  
14 things of that nature. That's the reason why I  
15 voted insufficient, okay. But I think it did --  
16 this discussion was confusing.

17 MEMBER STEINBERG: So I don't know if  
18 it's required, but I'd like to make a motion for  
19 a re-vote.

20 CHAIR WALDROP: Yes. And I think, it  
21 sounds like it's possible. So any objections to  
22 taking a re-vote, another vote?

1 (No audible response)

2 CHAIR WALDROP: Okay. So let us know  
3 when we're ready on the --

4 MEMBER TATUM: My understanding is  
5 we're one vote off being able to move forward in  
6 the insufficient category. Is that correct?

7 CHAIR WALDROP: Yes.

8 MEMBER TATUM: Thank you.

9 CHAIR WALDROP: Did you have a  
10 question, Christine? Did you have a question?  
11 Your card, sorry.

12 MR. TILLY: Okay, the polling is now  
13 open for a second vote on evidence. Your options  
14 are 1: high, 2: moderate, 3: low, and 4:  
15 insufficient. The votes are now 0 for high, 0  
16 for moderate, 0 for low, and 23 for insufficient.  
17 So the measure vote is insufficient.

18 The polling is now open to vote on  
19 whether the measure is insufficient evidence with  
20 an exception or whether no exception. The votes  
21 are 24 for insufficient evidence with exception  
22 and 0 for no exception. So the measure passes

1 evidence with exception.

2 CHAIR WALDROP: Okay, so we'll move on  
3 to considering gaps and opportunities for  
4 improvement. And I'll go back to Michelle  
5 please.

6 MEMBER CAUGHEY: This measure was  
7 difficult for many hospices to do because  
8 imbedded in it are several different -- the  
9 characterization of the pain, so they have to  
10 meet five elements out of six. Am I right about  
11 that? Oh, out of seven. And so there was great  
12 opportunity to improve at that level, but no  
13 disparities were seen.

14 CHAIR WALDROP: Okay. It's open to  
15 the floor. Any comments, thoughts, questions  
16 about gaps and opportunities for care,  
17 opportunities for improvement rather? Seeing  
18 none, we can move towards voting on opportunities  
19 for improvement.

20 MR. TILLY: The vote is now open on  
21 performance gap. Select 1 for high, 2 for  
22 moderate, 3 for low, and 4 for insufficient.

1 MS. ROILAND: Alice, can you submit  
2 your vote for performance gap? The options are 1  
3 high, 2 moderate, 3 low, and 4 insufficient.

4 MR. TILLY: The results are 11 voting  
5 high, 13 voting moderate, 0 voting low, 0 voting  
6 insufficient. The measure passes performance  
7 gap.

8 CHAIR WALDROP: Great. Thank you. So  
9 we'll move on to consider the scientific  
10 acceptability of the measure properties. We'll  
11 begin with reliability and reliability testing.  
12 Bob and Michelle?

13 MEMBER CAUGHEY: Very similar to the  
14 other measures at moderate reliability, inter-  
15 rater reliability was fairly high both for -- it  
16 was high for palliative care and moderately high  
17 for hospice.

18 CHAIR WALDROP: Okay, thank you. Any  
19 comments from the Committee, questions or  
20 concerns? I want to make sure Bob has a chance  
21 to --

22 MEMBER CAUGHEY: Yes, I should say

1 Bob, anything that you would like to add?

2 MEMBER ARCHULETA: No, I think that's  
3 -- what was said was the important part.

4 CHAIR WALDROP: I would like to ask  
5 Karen if you could clarify for us the preliminary  
6 rating as moderate and insufficient. Is that a  
7 typo on the measure evaluation script?

8 MS. JOHNSON: I think we have a little  
9 bit of a disconnect because the one that we're  
10 showing here --

11 CHAIR WALDROP: Is moderate.

12 MS. JOHNSON: -- is not checked.

13 CHAIR WALDROP: Okay.

14 MS. JOHNSON: So it may have been  
15 insufficient first, and you somehow or another  
16 may have an old version, but I'm not quite sure.

17 CHAIR WALDROP: I just wanted to  
18 clarify, thank you. So I believe we're ready to  
19 vote on reliability when Jean-Luc lets us in.

20 MR. TILLY: Yes, the polling is now  
21 open to vote on reliability. Select 1 for high,  
22 2 for moderate, 3 for low, 4 for insufficient.

1 The results are 3 voting high, 20 voting  
2 moderate, 0 voting low, and 1 voting  
3 insufficient. The measure passes reliability.

4 CHAIR WALDROP: Okay, we'll move on to  
5 validity, validity testing, and any threats to  
6 validity. And we'll go back to Michelle and Bob.

7 MEMBER CAUGHEY: So again, moderate as  
8 with the other measure. The only threats to  
9 validity had to do with the palliative side  
10 versus the hospice.

11 CHAIR WALDROP: Anything else to add,  
12 Bob?

13 MEMBER ARCHULETA: No, just that the  
14 statistics for palliative care to show the  
15 validity should be forthcoming, but it just isn't  
16 quite there yet.

17 CHAIR WALDROP: Okay, thanks. We open  
18 it to the committee. Any comments or thoughts or  
19 concerns, or questions from committee members?  
20 Seeing none, I think we're ready to vote on the  
21 validity of Measure 1637.

22 MR. TILLY: All right, to vote for

1 validity, select 1 for high, 2 for moderate, 3  
2 for low, and 4 for insufficient. Okay, the  
3 results are 0 voting high, 24 voting moderate, 0  
4 voting low, and 0 voting insufficient. The  
5 measure passes validity.

6 CHAIR WALDROP: Thank you. So we'll  
7 move on to feasibility or the ease of data  
8 collection and capture. And I'll go back to  
9 Michelle please.

10 MEMBER CAUGHEY: Can we do that other  
11 process that we did before? Yes? Okay.

12 CHAIR WALDROP: Thank you for  
13 reminding me, yes. I'll get this. So I want to  
14 remind you we can go back to our vote from  
15 earlier this morning when we looked at the  
16 dyspnea measure where we considered feasibility  
17 and usability and use and we can consider the  
18 same vote if we want to carry that forward.

19 Do I see any objections to carrying  
20 our vote forward? Seeing none, we can move on  
21 then to the overall vote of acceptability of this  
22 measure.



1 MR. TILLY: Polling is now open to  
2 vote for overall suitability for endorsement.  
3 Select 1 for yes and 2 for no.

4 The results are 24 voting yes and 0  
5 voting no. The measure is recommended.

6 CHAIR WALDROP: Okay. I believe that  
7 we have one measure left in this session, but we  
8 are going to stop for now and take a break. So I  
9 just want to thank you all very much for  
10 indulging me in this new role. Thank you so much  
11 for making this easier, and I look forward to  
12 talking with you over lunch, and we'll come back  
13 together afterwards.

14 CHAIR MORRISON: Actually, we're not  
15 going to take a break yet. Sorry, sorry, sorry.  
16 First we're going to do public comment on the  
17 morning session. So could I ask, Operator, could  
18 you open up the phones for public comment for  
19 people on the telephone lines?

20 OPERATOR: Yes, sir. At this time, if  
21 you would like to make a comment, please press  
22 star and then the number 1.

1 CHAIR MORRISON: And could I just ask  
2 you to state your name, where you're from, and  
3 your public comment succinctly.

4 OPERATOR: And at this time there are  
5 no public comments from the phone line.

6 CHAIR MORRISON: And then I would like  
7 to invite anybody in the back of the room, if you  
8 would like to make a comment, please step up to  
9 the microphone.

10 MS. AST: Hi, everyone. I'm Katherine  
11 Ast, the Director of Quality and Research for the  
12 American Academy of Hospice and Palliative  
13 Medicine.

14 AAHPM and other organizations from the  
15 National Coalition of Hospice and Palliative Care  
16 are here to express our strong support for the  
17 continued endorsement of all the measures brought  
18 forward for maintenance in this project.

19 Please take note of the letter we  
20 submitted prior to this meeting which highlights  
21 some of the issues our field faces that  
22 contribute to our lack of relevant measures,

1 particularly those with a true palliative care  
2 denominator.

3 What we want to emphasize today is how  
4 critical it is that we keep the endorsement of  
5 the measures we do have so they can be used to  
6 improve the quality of care for our patients and  
7 families and to enable our clinicians to  
8 participate in value-based reimbursement.

9 NQF, CMS, and the MAP have indicated  
10 through various publications and rulemaking that  
11 palliative care and end of life care represents a  
12 major gap in quality measurement.

13 Our field is very unique: since our  
14 patients are seriously ill, death is not always a  
15 negative outcome, can likely be a neutral or  
16 positive outcome.

17 We need measures that are flexible,  
18 take our uniqueness into account, emphasize care  
19 coordination, family meetings, goals of care, et  
20 cetera. The approach to measure development for  
21 our field cannot be cookie cutter.

22 In order to increase the usability of

1 the measures we have and expand the settings and  
2 populations for which they can be implemented, we  
3 need to keep working with what we have and keep  
4 the measures we do have endorsed.

5 We have so few outcome measures in our  
6 field, particularly patient-reported measures,  
7 and for good reasons. It's difficult to obtain  
8 the patient report in this population.

9 However, we do have NQF number 0209,  
10 the comfortable dying measure which is able to  
11 capture patient self-report of pain. Karen  
12 Johnson asked the question at the beginning of  
13 today's meeting that if we had outcome measures  
14 to capture enough aspects of the quality of care  
15 for patients with serious illness, would we still  
16 need process measures?

17 Unfortunately we have so few outcome  
18 measures that we couldn't possibly dispose of our  
19 process measures to measure quality. However we  
20 do have this outcome measure, and we believe we  
21 should keep it.

22 We believe that risk adjustment or

1 risk stratification is not critical for this or  
2 any other measures brought forth today although  
3 it is currently being explored for several of the  
4 measures.

5 The reason is the measures are used  
6 for comparison among similar providers, and  
7 there's no expectation that the performance be  
8 100 percent.

9 Benchmarking is a critical component  
10 to measuring the quality of care. And without  
11 measures to report and data to aggregate, we can  
12 never get to any benchmarks in our field.

13 There are certain processes that many  
14 believe should continue to be measured, even up  
15 to a rate of 100 percent. What does it mean for  
16 a measure to be topped out?

17 With such a new field finding its  
18 place in healthcare and in different settings, we  
19 think all the measures are far from being topped  
20 out even if they approach 100 percent  
21 performance.

22 In addition, many measures continue to

1 show a clear opportunity for improvement. Once  
2 we expand the measures to be reported in multiple  
3 settings and with a true palliative care  
4 denominator, then we can start to enable  
5 benchmarking and true comparison of providers.

6 We'll need to keep the endorsement of  
7 all the measures presented here today in order to  
8 see that goal become a reality. Thank you very  
9 much.

10 CHAIR MORRISON: Other comments from  
11 the back of the room? So I think everybody has  
12 earned a break for lunch. However, I am going to  
13 suggest that that be a very short ten minute grab  
14 lunch, use the restroom if you need it, and let's  
15 continue with a working lunch for the afternoon  
16 if that works for people. Thank you for a very  
17 great morning. Hard work.

18 (Whereupon, the above-entitled matter  
19 went off the record at 1:05 p.m. and resumed at  
20 1:26 p.m.)  
21  
22

1 A-F-T-E-R-N-O-O-N S-E-S-S-I-O-N

2 1:26 p.m.

3 CHAIR WALDROP: Okay. Welcome back,  
4 everyone. We are going to finish this round by  
5 considering Measure 1628, Patients with advanced  
6 cancer screened for pain in outpatient visits. I  
7 will turn to our measure developer, who is  
8 joining us by phone, first, and then I will go to  
9 our discussants. We have two discussants present  
10 with us, Karl and Tracy, and then we have Amy  
11 Sanders on the phone. So I would like to begin  
12 by asking our measure developer, are you there  
13 and would you like to share briefly a little bit  
14 about this measure?

15 MR. LORENZ: This is Karl Lorenz. I  
16 don't know if I'm the only one who's present, is  
17 that the case? I don't know if Neil is on the  
18 line.

19 MR. WENGER: No, I'm here too, but for  
20 this Measure, let me let you talk, Karl.

21 MR. LORENZ: Okay. So this -- I think  
22 the measure we're looking at currently is routine

1 screening for pain. And this comes from the  
2 Cancer Quality ASSIST Indicator Set and in  
3 general it relies on evidence related to the use  
4 of screening for pain in every intervention  
5 related to either critical intervention or  
6 quality improvement in the field of pain  
7 research. And although -- I just would stress as  
8 well that in general adherence to this tends to  
9 be moderately high, but evidence looking at  
10 facility level variations still shows important  
11 sub-populations of patients and of facilities  
12 that are non-adherent to it, even in the  
13 Department of Veterans Affairs, in previous  
14 published works. But in general, it is intended  
15 to emphasize the need to screen for pain  
16 routinely in advanced illness.

17 CHAIR WALDROP: Thank you very much.  
18 So I would like to move to our discussants and  
19 ask, I believe Karl is going to start us off  
20 looking at the importance of this measure and of  
21 reporting it.

22 MEMBER STEINBERG: Great. Well, thank



1       you and I'm going to do the best I can with my  
2       eyes and if it doesn't work out, I may need to  
3       ask for help from my co-discussant. So this is  
4       somewhat similar to 1634 that we already  
5       discussed, except that this is a measure in the  
6       outpatient setting and this is for people with  
7       advanced cancer. It's a process measure. And  
8       essentially, they have to be screened for pain  
9       with a standardized tool at every outpatient  
10      visit. It's a maintenance measure and it's --  
11      essentially, the evidence, there's some  
12      systematic reviews, there's not a lot of  
13      empirical evidence, but the idea behind it being  
14      just like the other measures that in order to  
15      treat pain, you have to assess whether they're  
16      having pain or not. And last time, it was  
17      Insufficient, but with an exception. I don't  
18      know if there's any specific questions about it.

19                   CHAIR WALDROP: Okay. So let me ask  
20      Amy Sanders and Tracy Schroepfer if you have  
21      anything else you want to add about the evidence  
22      to this measure?

1 MEMBER SCHROEPFER: This is Tracy. I  
2 don't.

3 CHAIR WALDROP: Amy, are you there?

4 MEMBER SANDERS: It took me a second to  
5 find you to unmute you. I don't have anything to  
6 add in particular, other than that the Developer  
7 stated that there was no new evidence since this  
8 measure was initially endorsed in 2012.

9 CHAIR WALDROP: Thank --

10 MEMBER STEINBERG: Sorry --

11 CHAIR WALDROP: Okay.

12 MEMBER STEINBERG: -- one other thing.  
13 We actually did get some additional evidence that  
14 was submitted and it's in the packet now. And  
15 probably has to do more with kind of gap analysis  
16 and so on. But what was interesting was that  
17 this was a VA study from 2014 from Oishi and it  
18 indicates that basically the mean on this measure  
19 was 98 percent in the VA clinics. So the  
20 developers say that there are still some gaps,  
21 and whether it's topped out or not, it's just  
22 something that's probably worth mentioning.

1 CHAIR WALDROP: Thank you. So, did you  
2 want to comment on the Staff's recommendation of  
3 Insufficient with an Exception? Any thoughts  
4 about that or --

5 MEMBER STEINBERG: That seems  
6 reasonable.

7 CHAIR WALDROP: Okay. Comments from --

8 MEMBER SANDERS: Agree.

9 CHAIR WALDROP: Oh, Amy, sorry.

10 MEMBER SANDERS: I agree.

11 CHAIR WALDROP: Okay, thanks.

12 MEMBER SANDERS: But it seems  
13 reasonable, Insufficient with an Exception.

14 CHAIR WALDROP: Okay. Comments,  
15 questions from the Committee? Okay. All right.  
16 Then I think that moves us in the direction of  
17 voting on the evidence for measure 1628. Jean-  
18 Luc, when you're ready.

19 MR. TILLY: That's right. The polling  
20 is open to vote on evidence. Select 1 for High,  
21 2 for Moderate, 3 for Low, and 4 for  
22 Insufficient.

1 MS. ROILAND: Hi, Amy, if you could  
2 text your vote to Jean-Luc now, that would be  
3 great. Thanks.

4 MEMBER SANDERS: I have texted, it's  
5 the perils of the new cell phone, I'm all thumbs,  
6 apologies.

7 MS. ROILAND: That's okay. Thank you,  
8 though.

9 MR. TILLY: All right. The voting is  
10 one voting High, two Moderate, zero Low, and 21  
11 Insufficient. So the measure is voted  
12 Insufficient. So the voting is now open to  
13 select if the measure passes with an exception.  
14 So select 1 for Insufficient Evidence with  
15 exception, select 2 for no exception.

16 MS. ROILAND: Amy, did you submit your  
17 vote via text? And, Bob, did you text Jean-Luc  
18 your vote?

19 MEMBER ARCHULETA: Yes.

20 MS. ROILAND: Okay.

21 MR. TILLY: All right. The vote is 24  
22 voting for Insufficient Evidence with an

1 Exception and zero voting no exception. So the  
2 Measure passes Evidence with Exception.

3 CHAIR WALDROP: Great, thank you. So  
4 that moves us on into considering gaps in care,  
5 opportunities for improvement and disparities,  
6 and also a place where we might look at some of  
7 that additional information that Karl mentioned  
8 we have now from the Developer. Karl?

9 MEMBER STEINBERG: Yes. So as far as  
10 the gaps, the data that are listed in the  
11 original, in the document here, indicate that  
12 there is still a significant gap. Like I said,  
13 that 2014 study, at least in the VA, indicated  
14 perhaps less of a gap with 98 percent mean, but  
15 it seems like an important area.

16 CHAIR WALDROP: Okay.

17 MEMBER STEINBERG: And it indicates  
18 that perhaps having this Measure has resulted in  
19 an improvement already.

20 CHAIR WALDROP: I just want to ask if  
21 you might comment, or if Karen wants to, on the  
22 Staff's recommendation of Insufficient for the

1 preliminary rating of opportunities for  
2 improvement.

3 MS. JOHNSON: We went with Insufficient  
4 on this just because the data that were provided  
5 originally were quite old, they were more than  
6 five years. Oh, sorry. We chose Insufficient  
7 the first time around because the data that were  
8 initially provided were more than five years old,  
9 so it didn't really speak to the current gap that  
10 might be out there. So, that's why Insufficient.  
11 In terms of the papers that were added after the  
12 work group call, I might be curious to ask if  
13 Karl wants to speak to the gap in the 2014  
14 publication. Is there anything that you want to  
15 tell the Committee about that publication in  
16 terms of gap?

17 MEMBER STEINBERG: Well, I mean, this  
18 is only for VA facilities nationwide and it was  
19 essentially about 6,800 visits, out of which  
20 about 6,600 actually had the assessment done, the  
21 pain assessment. So, that was -- the mean was 98  
22 percent. So, it seems like maybe at least the VA

1 is doing it well, but I don't know how much that  
2 extrapolates to other outpatient cancer settings  
3 and so on. I mean, it doesn't make it any less  
4 important.

5 CHAIR WALDROP: Anything further --

6 MEMBER SANDERS: This is Amy. I have  
7 a comment too when we get to disparities, which  
8 is sort of a subset of gaps in care.

9 CHAIR WALDROP: Now would be good.

10 MEMBER SANDERS: Okay. So there was a  
11 paper in the Journal of General Internal Medicine  
12 about a year ago that disparities in -- that  
13 collection of data in EMRs for race, ethnicity,  
14 and preferred language is terrible. I just have  
15 some quick notes here, so I don't have the actual  
16 data to provide to you, but, and I realize that  
17 reasoning by extrapolation is not exactly  
18 rigorous, but if EMRs are not even documenting  
19 the basic demographic categories that would  
20 define a disparity, then I think it's exceedingly  
21 unlikely that pain or anything else is being  
22 measured on a regular basis according to some

1 sort of disparity split group analysis or  
2 anything like that.

3 CHAIR WALDROP: Thank you. Anything  
4 else from Karl or Tracy on this? The disparity  
5 measure? Okay. Comments from the Committee?  
6 Questions? Seeing none, I believe that moves us  
7 into the place of voting on gaps and  
8 opportunities for improvement. Jean-Luc?

9 MR. TILLY: That's right. Polling is  
10 open, please vote for Performance Gap, 1 High, 2  
11 Moderate, 3 Low, and 4 Insufficient. And I'm  
12 sorry, I think that we'll need just one more in  
13 the room, if you all could --

14 MS. ROILAND: Also, Alice, if you could  
15 submit your voting, I'd appreciate it. Thank  
16 you.

17 MR. TILLY: And, Bob, if you could send  
18 a quick text with your vote here. Thanks. So  
19 the results are zero voting High, 15 voting  
20 Moderate, two voting Low, and seven voting  
21 Insufficient. The Measure passes.

22 CHAIR WALDROP: Okay. Thank you.



1 Moving on, we will now consider the scientific  
2 acceptability of Measure properties. And we'll  
3 start by looking at Reliability and the  
4 reliability specifications and then move into  
5 reliability testing. Karl?

6 MEMBER STEINBERG: Sure. So, the  
7 Reliability, I mean, this is basically a yea or  
8 nay, was the patient screened or not. As you  
9 might expect, the kappa is very high, it's 80.81  
10 or, no, sorry, 80.86, so it seems pretty reliable  
11 to me. And the people who read it before  
12 recommended Moderate and that seems to be  
13 appropriate as far as I can tell.

14 CHAIR WALDROP: Anything from Amy or  
15 Tracy? Nothing from Tracy. Amy?

16 MEMBER SANDERS: I have nothing to add.

17 CHAIR WALDROP: Okay. Thank you. Let  
18 me open it to the Committee. Any comments or  
19 thoughts? Bob? Rob?

20 MEMBER SIDLOW: My one comment on the  
21 specification is that, this Measure is sort of  
22 behind the times in the sense that it's really

1 narrowed to stage four cancer whereas in feet on  
2 the ground, it's happening much more broadly.  
3 So, in terms of its actual usability, I'm  
4 wondering about that.

5 CHAIR WALDROP: Okay.

6 MEMBER STEINBERG: And we actually  
7 discussed that in the work group, but apparently  
8 it's a lot more work to bring in other  
9 additional, an additional population for this.  
10 But we certainly agree in principle.

11 CHAIR WALDROP: Okay. Other comments?  
12 Okay. Seeing none, we can move towards looking  
13 to vote on Reliability.

14 MR. TILLY: So to vote on Reliability  
15 for 1628, please select 1 for High, 2 for  
16 Moderate, 3 for Low, and 4 for Insufficient. So  
17 the results are two voting High, 19 Moderate, two  
18 Low, and one Insufficient. The Measure passes  
19 Reliability.

20 CHAIR WALDROP: Okay, thank you.  
21 Moving on to consider Validity, we'll look at  
22 specifications and validity testing and then any

1 threats that there are to the validity of this  
2 Measure. Karl?

3 MEMBER STEINBERG: Yes. So, as far as  
4 validity testing, initially there was concern  
5 that we didn't get the information on how the  
6 expert panels conducted their validity assessment  
7 and the Measure Developers did produce that  
8 information, which is available in the packet.  
9 So, I think that's been remedied, its face  
10 validity. And, let's see, so that's that. As  
11 far as threats to validity, one of the exclusions  
12 on this Measure was that people had to survive at  
13 least 30 days after a cancer diagnosis.

14 Personally, I don't know exactly why  
15 that would be all that relevant, because you can  
16 still screen for pain whether the person is about  
17 to die or not, but they didn't say how many of  
18 the people died within 30 days, so it might be  
19 worth not having that exclusion, but I don't  
20 think it's a particularly large threat to  
21 validity of the Measure. And I think that's  
22 about it. It was considered Insufficient before

1 by the previous reviewers and I think that the  
2 Measure Developers did remedy the lack of  
3 information about expert consensus and so on and  
4 their methods. So I'm thinking Moderate as far  
5 as, that would be my recommendation.

6 CHAIR WALDROP: Thank you for that.  
7 Anything further on the shift from Insufficient  
8 to Moderate or anything about? Tracy or Amy?

9 MEMBER SCHROEPFER: I agree.

10 CHAIR WALDROP: Okay. Amy?

11 MEMBER SANDERS: I'm not so sure that  
12 face validity, and even by the modified Delphi  
13 methods, is really sufficient to bridge the gap  
14 between Insufficient and Moderate.

15 CHAIR WALDROP: Okay. Let me open that  
16 for comments. Rob, did you have more to say or  
17 was that from before? Okay. Anybody, any other  
18 comments?

19 MEMBER STEINBERG: I just think looking  
20 at the algorithm, that -- so if the results are  
21 not provided, then it's automatically  
22 Insufficient, but since they did provide the

1 results, that was my reasoning.

2 MEMBER SCHROEPFER: Well, and I thought  
3 that, and correct me if I'm wrong, we said this  
4 morning that face validity is considered Moderate  
5 by NQF. Is that right, Karen?

6 MS. JOHNSON: Yes. We do accept face  
7 validity. We have some exceptions though, it has  
8 to be face validity with a measured score, it has  
9 to be systematically assessed, which they've done  
10 with their modified Delphi process, and they have  
11 to tell us about their experts, how did they do  
12 it, and they need to tell us what the actual  
13 results are, not just say that it was valid, but  
14 give us some details about the results. And I  
15 believe they, in their additional materials, they  
16 were able to do that.

17 MEMBER SCHROEPFER: Thank you. Because  
18 I do think face validity is a weak validity, but  
19 I do feel like they did answer our questions and  
20 provide us the additional information we needed.

21 CHAIR WALDROP: Okay. Any other  
22 comments from the Committee? Seeing none, let's

1 move to voting on the validity of Measure 1628.

2 MR. TILLY: So this time your voting  
3 options have changed a little bit actually  
4 because the validity testing is face validity  
5 only. Your options are 1 for Moderate, 2 for  
6 Low, and 3 for Insufficient, so there is no High  
7 option. By all means, if you accidentally -- you  
8 can press a different key and it will update your  
9 vote, yes.

10 MS. ROILAND: Alice, could you send me  
11 your vote, please?

12 MS. LIND: I thought I had, I'll try  
13 again.

14 MR. TILLY: So, the voting results are  
15 20 voting Moderate, three voting Low, and one  
16 voting Insufficient. So the Measure passes  
17 Validity.

18 CHAIR WALDROP: Thank you. So we'll  
19 move on to considering Feasibility or  
20 implementation issues of 1628. I'll turn again  
21 to Karl, please.

22 MEMBER STEINBERG: Yes. So, this,

1 again, it's kind of a yea or nay, was there  
2 evidence of a quantitative screening tool, a  
3 validated screening tool in the record? It was  
4 felt by the reviewers to be moderately feasible.  
5 That seems to be reasonable to me.

6 CHAIR WALDROP: Okay. Anything from  
7 Amy or Tracy? Tracy says, no. Amy, any  
8 thoughts?

9 MEMBER SANDERS: No, thanks.

10 CHAIR WALDROP: Okay. Let me open this  
11 to the Committee. Any questions about  
12 Feasibility, consideration of this issue? Seeing  
13 none, we'll move to voting on the Feasibility of  
14 1628.

15 MR. TILLY: So, the polling is now open  
16 for Feasibility. Select 1 for High, 2 for  
17 Moderate, 3 for Low, and 4 for Insufficient.  
18 We're actually looking for just one more vote in  
19 the room, so if you all could try again. Thank  
20 you. All right. And the results are two voting  
21 High, 22 voting Moderate, zero voting Low, and  
22 zero voting Insufficient. The Measure passes

1 Feasibility.

2 CHAIR WALDROP: Okay. That brings us  
3 to considering Usability and Use, so the impact,  
4 improvement, and unintended consequences of a  
5 Measure. I'll go back to Karl, please.

6 MEMBER STEINBERG: Yes. And since it's  
7 a maintenance Measure, I guess we're supposed to  
8 have more of a focus on the use and usefulness.  
9 As of now, it's not a publically reported  
10 Measure, it's not currently being used in an  
11 accountability program, although at least the  
12 California Department of Healthcare Services is  
13 planning to start using this Measure. There were  
14 no unexpected findings or potential harms. And  
15 it was rated as Low and I don't see anything that  
16 suggests, as of now, that would be different.

17 CHAIR WALDROP: Karen, did you want to  
18 comment on the Staff's consideration of this as  
19 Low?

20 MS. JOHNSON: It really does go back to  
21 it not being -- can somebody turn off --

22 MEMBER STEINBERG: Sorry, I'll turn



1 mine off.

2 MS. JOHNSON: It really does go back to  
3 not being in use and also not having the data to  
4 be able to see if there's been improvement over  
5 time, which of course is related to not being in  
6 use. So that's why we chose Low.

7 CHAIR WALDROP: Thank you. Any other  
8 questions or comments from the Committee?

9 MEMBER SIDLOW: I have a comment.

10 CHAIR WALDROP: Rob?

11 MEMBER SIDLOW: I think that there is  
12 a potential negative downstream effect of this,  
13 given the 30 day specification and the limitation  
14 to stage four. The potential downstream is that  
15 an organization might focus too narrowly, which  
16 sort of defeats the purpose of, I think, the  
17 Measure largely. I support the Low, basically.

18 CHAIR WALDROP: Okay, thank you.

19 Woody, did you have -- oh, sorry --

20 MEMBER MOSS: I think that's old.

21 CHAIR WALDROP: -- it's a card. Any  
22 other comments from the Committee about Usability

1 and Use of 1628? All right. That moves us  
2 towards our vote on Usability and Use. Jean-Luc?

3 MR. TILLY: So, to vote on Usability  
4 and Use for 1628, select 1 for High, 2 for  
5 Moderate, 3 for Low, and 4 for Insufficient  
6 Information. So the results are zero voting  
7 High, nine voting Moderate, 15 voting Low, and  
8 zero voting Insufficient Information. So the  
9 Measure does not pass Usability and Use.

10 CHAIR WALDROP: Okay. My understanding  
11 is that we do continue on an overall vote though,  
12 even though it doesn't pass on that measure. So  
13 we'll move on to the overall vote of the  
14 acceptability of 1628.

15 MEMBER HANDZO: Yes. I would find it  
16 helpful if, potentially, Dr. Lorenz could address  
17 this question of usability going forward. That  
18 seems to be a critical issue here in terms of  
19 NQF. Karen, am I right about that?

20 MS. JOHNSON: Just a reminder, even  
21 though you voted Low for Usability and Use, that  
22 is not currently a must pass criterion as

1 Evidence or Reliability and Validity is.

2 However, that said, our new maintenance process,  
3 we are putting more emphasis on Usability and  
4 Use. So, again, it's a balance thing. I think  
5 hearing from Dr. Lorenz would be actually pretty  
6 interesting. Dr. Lorenz, are you still on the  
7 line? Or Neil, either one?

8 MR. WENGER: I am here. I think Karl  
9 is better able to address usability with this  
10 Measure.

11 MR. LORENZ: I'm sorry, Neil, if I need  
12 to say something, I will need to reattend, I'm  
13 holding multiple meetings, but I'm happy to jump  
14 in. Just let me know, I'm here now.

15 MR. WENGER: They're asking about  
16 usability of the Measure.

17 MR. LORENZ: And which Measure are we  
18 on now?

19 MR. WENGER: The same one.

20 CHAIR WALDROP: 1628.

21 MR. LORENZ: Oh. Usability of the  
22 Measure, I think it has not been used for quality

1 improvement, if that's the standard.

2 MS. JOHNSON: I guess maybe our  
3 question is, do you have any idea why folks --

4 MR. LORENZ: Why it's not been used?

5 MS. JOHNSON: Yes. I mean, folks  
6 around the table seem to like the Measure, but  
7 it's not being picked up. Any -- just curious --

8 MR. LORENZ: I think many people just  
9 assume that advanced cancer patients are having  
10 their pain measured, although it turns out not to  
11 be uniformly true. And the vast majority of  
12 emphasis now these days in pain management is on  
13 reducing opioid use and on minimizing  
14 prescriptions in primary care. So, I just think  
15 that other than us, there just are not system  
16 champions of the cause, per se.

17 CHAIR WALDROP: Thank you for that.  
18 Any other comments or concerns? Christine?

19 MEMBER RITCHIE: When do we talk about  
20 comparability of Measures?

21 MS. JOHNSON: That would be later.

22 CHAIR WALDROP: Any other comments or

1 questions? I think that signifies we're ready to  
2 vote on our overall satisfaction with this  
3 Measure.

4 MR. TILLY: That's right, yes. So the  
5 question is, does the Measure meet NQF criteria  
6 for endorsement? Select 1 for Yes and 2 for No.  
7 The results are 24 in support of the Measure  
8 voting Yes and zero voting No. So the Measure  
9 passes.

10 CHAIR WALDROP: Thank you. So that  
11 brings us to the end of the first candidate  
12 Measures grouping. And I'll pass the baton to  
13 Sean.

14 CHAIR MORRISON: So you guys are stuck  
15 with me for the next little while. We're going  
16 to move to 1617, which is Patients Treated with  
17 an Opioid who are Given a Bowel Regimen. Neil,  
18 Karl, it's Sean Morrison, I'm not sure which one  
19 of you is going to talk about this one as a  
20 Developer.

21 MEMBER CASS: It's actually me. 1617?

22 MR. LORENZ: Yes, I can --

1 MS. JOHNSON: Sean, do you mind if I  
2 interrupt?

3 CHAIR MORRISON: I'm sorry, go ahead.

4 MS. JOHNSON: That's okay. This was in  
5 smaller print here, so you probably didn't see  
6 it, but actually, Christine, to your point, let's  
7 talk about related and competing Measures now for  
8 pain. We just went through the pain Measures.  
9 There were three of them. And I'm not quite sure  
10 -- I have a couple of extra slides. Can you  
11 bring those up, Jean-Luc? I'm just going to run  
12 through this. This is probably going to be a  
13 fairly short conversation, but maybe not. And  
14 apologies, Sean, for jumping in.

15 CHAIR MORRISON: Go right ahead.

16 MS. JOHNSON: You guys saw this slide  
17 this morning, so I just wanted to bring this back  
18 to your attention. We've now looked at the two  
19 screening Measures from UNC, as well as the one  
20 we just talked about, 1628, and we had looked at  
21 0209 earlier today as well, the Comfortable Dying  
22 Measure. Let's go to the next slide. So, the

1 Comfortable Dying Measure right now actually has  
2 gone down. So that means that we are actually  
3 not going to talk about related and competing  
4 with this Measure. If it comes back after our  
5 comment period and you guys decide to move  
6 forward with recommending endorsement for that  
7 Measure after you see the new data that Carol may  
8 be able to bring to us, we probably would have  
9 this conversation at that point. Okay.

10 That said, let's go to the next slide.  
11 So, pain Measures in the ambulatory setting. Let  
12 me orient you to this table really quickly. You  
13 have seen and actually have just talked about  
14 Measure 1628. It's about screening for pain, the  
15 level of analysis is several different things  
16 that a facility plans integrated systems, and  
17 it's focused on adult patients with advanced  
18 cancer. Now, we have some other Measures that  
19 are in our portfolio regarding pain in the  
20 ambulatory setting.

21 Now, you guys have not seen these, you  
22 know that because you haven't looked at these,

1 right? So we can't really ask you to talk about  
2 what we would call best in class, we can't ask  
3 you at this point to say, this one is better than  
4 that one or if we had this one, we wouldn't need  
5 the other ones, that sort of discussion.

6 However, I did want to point out some of the  
7 differences across these Measures. Particularly,  
8 I think, in the denominators, and we've gotten to  
9 some of this already I believe in the discussion.

10 What we would like from you guys is,  
11 do you see anything on this screen, particularly  
12 around the numerator or the denominator or the  
13 exclusions, that you could offer as  
14 recommendations for what we call harmonization?  
15 So, when we talk about harmonization, we talk  
16 about making Measures as aligned as they can be,  
17 either in the numerator or in the denominator, in  
18 the exclusions, et cetera. It is a little tough,  
19 most of these are looking at the individual  
20 level.

21 But really I think we just want to  
22 have a conversation now, do you see the need for



1 four ambulatory pain Measures? If you could  
2 tweak your magic wand and have something, what  
3 would you see? Would you have something  
4 different than what you have on the screen in  
5 front of you? So, let me just stop there and  
6 let's just chat. Christine?

7 MEMBER RITCHIE: Yes. So, this is what  
8 I was alluding to earlier. It seems like the  
9 numerators for 1628 and 0384 could be harmonized.

10 MS. JOHNSON: Okay. If those were  
11 harmonized, would we need two of those Measures?  
12 Arif?

13 MEMBER KAMAL: So, I mean, I don't know  
14 what the answer is of where we want to go, but  
15 1628 is those with advanced incurable disease on  
16 all visits, 0384 is independent of stages, as I  
17 read it, but actively receiving therapy. So,  
18 meaning the gaps are a stage four patient who is  
19 not receiving therapy would not fall under 0384,  
20 right? And likewise, a patient not receiving --  
21 a stage four patient -- you know what I mean.

22 MS. JOHNSON: Yes.

1                   MEMBER KAMAL: So, I mean, I don't know  
2                   what the true answer is of where we want to be.  
3                   It seems that we're arguing as palliative care  
4                   clinicians that stage really has nothing to do  
5                   with it, so I can see where 0384 seems to make  
6                   sense, but at the same time, we're not saying  
7                   that somebody needs to be actively receiving  
8                   therapy to have a pain assessment either, and  
9                   that's where I think 0384 falls short. And then  
10                  0420 requires the documentation of a plan, which  
11                  just from a COC, Commission on Cancer  
12                  accreditation, Joint Commission, and NCCN  
13                  guideline perspective of what cancer centers are  
14                  doing, they're not documenting the plan. So that  
15                  would be a stretch Measure in the current sense  
16                  for cancer practices.

17                 MS. JOHNSON: Amy?

18                 MEMBER SANDERS: I don't have anything.

19                 MEMBER BERMAN: Sorry, this is the  
20                 other Amy. Hi. So 0383, I'm wondering if that  
21                 one might be able to, in terms of the  
22                 denominator, be the stronger indicator? If we

1 were to look across these, maybe they could be  
2 harmonized toward that denominator because it is  
3 more specific about process and multiple  
4 processes where that pain would then be assessed  
5 and, in this case, have an appropriate care plan.  
6 So I'm kind of wondering whether there needs to  
7 be a separate screening assessment and care plan,  
8 but rather that it is screened at all of those  
9 encounters and has the appropriate care plan, the  
10 0383 may be the higher level of saying that we've  
11 accomplished those things.

12 MS. JOHNSON: So, a couple things just  
13 to point out, and this is, I think, really to get  
14 you guys thinking about having a lot of Measures  
15 that are doing pretty much the same thing, right?  
16 All of these are looking at pain in an ambulatory  
17 setting. They're doing it a little differently  
18 in terms of the data source, but I think one of  
19 the take home points, and, again, just to get you  
20 thinking in this way, by looking at the 0420, you  
21 see that it is possible to construct a Measure  
22 that looks at assessment and follow-up at the

1 same time, right? So you don't have to split  
2 them out, okay? So that's one thing to think  
3 about.

4 Another thing that you could consider  
5 is you can definitely look very closely at, as  
6 Amy was saying, the narrow groupings of patients,  
7 but 0420 actually doesn't do that, it just says,  
8 any patient 18 or older. So, this Measure would  
9 work whether you have stage four or not or  
10 whether you're on chemo, radiation, or not. So,  
11 that's the kind of thing that we want you to  
12 think about because what we hear in the field is  
13 there's a lot of Measures out there and that it's  
14 confusing and can be labor intensive to have to  
15 work on different Measures.

16 So, as overseers of the portfolio, you  
17 guys could actually potentially help the field by  
18 saying, look, this is what we'd really like to  
19 see. Does that mean you'll get what you'd like  
20 to see? Not necessarily, different Developers  
21 have different reasons. And again, we have some  
22 differences in terms of levels of analysis and

1 data source and that sort of thing, but again,  
2 that's the kind of discussion I think that would  
3 be helpful to have, because what we want to do is  
4 push the field forward. And -- Sean?

5 CHAIR MORRISON: Yes. I just checked,  
6 because I didn't want to trust my brain on this,  
7 and I don't know if this is the appropriate time,  
8 but 0420 is already in the PQRS program. And so,  
9 to Arif's point, it is a Measure that's already  
10 in the reporting program that people are being  
11 held responsible for reporting. So I'm not so  
12 sure given that it really encompasses 1628, 0384,  
13 0383, and takes it a step further, that it  
14 doesn't harmonize all three of them across a much  
15 wider patient population. And it's already gone  
16 through the MAP process to get into PQRS.

17 MS. JOHNSON: Amy?

18 MEMBER BERMAN: So, just a clarifying  
19 question, does 0420 identify at specific times or  
20 could it be one time? I'm looking at the Measure  
21 and without any specificity, the kind of  
22 specificity for example in the denominator of

1 0383, I'm just wondering whether one could  
2 achieve a low bar of a one-time assessment and  
3 have fulfilled the Measure?

4 MS. JOHNSON: And that is actually a  
5 great point, and I don't have the details of the  
6 Measure. If you guys were actually looking and  
7 evaluating that Measure, we would have that.  
8 That's why I'm not asking you actually to do a  
9 best in class kind of thing. But that's a good  
10 point, and I can look into that and get back to  
11 you. I don't know the answer right off. But I  
12 think that is a very good point that the  
13 screening Measure that you looked at is every  
14 visit it should be done.

15 I'll also point out that even if you  
16 guys were looking at all four of these Measures  
17 in this project, I actually wouldn't have you try  
18 to choose best in class between 1628 and the  
19 other Measures because the level of analysis is  
20 different and we have, as NQF, said that while we  
21 would consider those competing Measures, we would  
22 have the same conversation that we always have.

1 So we just said, we won't even have that  
2 conversation. Right now we understand that  
3 there's different levels of analysis and  
4 different Measures sometimes are needed for that,  
5 not always, but sometimes. Does this make sense,  
6 the kind of things that I'm asking you to at  
7 least think about? Arif, do you have something?

8 MEMBER KAMAL: No, it does, sorry. And  
9 I had to clarify this in my own brain to make it  
10 work. So, Patient Reported Outcome Performance  
11 Measure can be a misnomer if you focus on the O,  
12 and this is actually classified as a Process  
13 Measure because it's not actually measuring a  
14 change in a patient's health state, right? So I  
15 wanted to actually give this more credit than  
16 maybe it's due, the 0420 being an Outcome  
17 Measure, because we're in this sort of continuous  
18 search for an Outcome Measure for palliative care  
19 that works for everybody, and I just had to  
20 clarify in my head that this is actually very  
21 much a Process Measure, none of these are truly  
22 Outcome Measures.

1 MS. JOHNSON: And you know, I did this  
2 very, very, very early this morning, so now I'm  
3 wondering if it is a PROPM and -- do you  
4 remember, Sean? That might be a mistake on my  
5 part.

6 CHAIR MORRISON: I can't.

7 MS. JOHNSON: Marcia may look it up for  
8 us. Nothing is riding on this, so I can get back  
9 to you on the details. Just so you know, at some  
10 point, as members of our standing Committee  
11 overseeing the portfolio, at some point, we may  
12 come to you and we may say, here are these  
13 Measures and, if you can, pick the best one. And  
14 what that means is, you would endorse one and not  
15 endorse another, okay? Again, we're not asking  
16 you to do that right now, but that is something  
17 that we may do in the future. And it's hard,  
18 because often folks feel funny about taking  
19 endorsement away. Any other questions? I don't  
20 want to belabor this part of the discussion, but  
21 I think it is valuable to be thinking about the  
22 portfolio.



1 CHAIR MORRISON: Let me just clarify,  
2 it is a Process Measure, not a PROPM.

3 MS. JOHNSON: Apologies for that.

4 MEMBER CASS: Karen, you said we might  
5 be asked to choose one best, but how about  
6 combining? Is that another --

7 MS. JOHNSON: That would be possibly  
8 even better --

9 MEMBER CASS: Better?

10 MS. JOHNSON: Yes. Because --

11 MEMBER CASS: Yes.

12 MS. JOHNSON: -- if you combine, you  
13 could potentially reach a broader swath of  
14 patients or levels of analysis, et cetera.

15 MEMBER CASS: Each one has elements  
16 that are --

17 MS. JOHNSON: Yes.

18 MEMBER CASS: -- better than the other.

19 MS. JOHNSON: Yes. So, a  
20 recommendation for combining in some way would be  
21 -- again, it would potentially be a  
22 recommendation that might not be taken, but

1 sending a strong signal from this group, I think  
2 is something that Developers would pay attention  
3 to. All right. I think we're done with related  
4 and competing with pain Measures, at least for  
5 now. So now, Sean?

6 CHAIR MORRISON: All right. So let's  
7 go back to 1617, which is Patients Treated with  
8 an Opioid who are Given a Bowel Regimen. And  
9 again, I'm not sure, Neil or Karl, who would like  
10 to describe this one for us?

11 MEMBER CASS: And actually, it's mine.

12 CHAIR MORRISON: Actually it's not,  
13 sorry.

14 MEMBER CASS: It's not.

15 CHAIR MORRISON: It's the Developers.  
16 I'm asking --

17 MEMBER CASS: Oh, I'm sorry.

18 CHAIR MORRISON: That's all right.

19 MEMBER CASS: I apologize. I didn't --

20 CHAIR MORRISON: That's all right.

21 MEMBER CASS: -- see anybody sitting  
22 over there. I'm glad they're here, though.

1 Thank you.

2 CHAIR MORRISON: Karl, Neil --

3 MR. WENGER: Yes.

4 CHAIR MORRISON: -- who's with us?

5 MR. WENGER: This is Neil.

6 CHAIR MORRISON: Hey, there.

7 MR. WENGER: So this is a longstanding  
8 Measure that focuses upon the use of a bowel  
9 regimen for patients who are receiving more than  
10 one opioid prescription. And I don't actually  
11 know what else you want me to say about it.

12 CHAIR MORRISON: That is a good start,  
13 Neil, and I'm sure we'll have questions as we  
14 move forward. So, now I have Cleanne and I have  
15 Arif. You're on.

16 MEMBER CASS: Okay. I apologize.

17 CHAIR MORRISON: We're going to start  
18 with Evidence.

19 MEMBER CASS: All right. Karl's  
20 another member of my work group, so it confused  
21 me, the two names. So this is 1617, it is a  
22 Process Measure, and it's a maintenance Measure.

1 We're looking at the percentage of vulnerable  
2 adults that are treated with an opioid that are  
3 also offered or prescribed a bowel regimen or  
4 documentation of why it was not needed. So,  
5 looking at the evidence, the Developer did  
6 provide very good evidence at the beginning when  
7 this was first presented.

8 Evidence from the AGS Panel on  
9 Persistent Pain in Older Adults, which is  
10 Evidence Grade A, and then evidence from the  
11 American Pain Society, which was a strong  
12 recommendation. But there is no new evidence and  
13 the Developer attests that there's been no  
14 changes in the evidence since the Measure was  
15 last evaluated. Guidance from the evidence  
16 algorithm recommended a Moderate rating on this.

17 CHAIR MORRISON: And my understanding,  
18 Karen, correct me if I'm wrong, unless Arif has  
19 major comments, is because there's no change in  
20 the evidence, we can actually pass through this  
21 and move on to gaps.

22 MS. JOHNSON: As long as the Committee

1 agrees that there haven't been --

2 CHAIR MORRISON: As long as --

3 MEMBER CASS: Yes, and --

4 CHAIR MORRISON: -- the Committee  
5 agrees.

6 MEMBER CASS: The Developer offered the  
7 rationale that there's a strong relationship  
8 between the process of care and positive outcomes  
9 for the patient, so I think the evidence is  
10 clear. So, moving on to gaps. There was some  
11 data presented for performance gap requirements.  
12 And the studies were reported to be relatively  
13 recently, but they were both more than five years  
14 old. There was no data on disparities, but  
15 because the data provided was more than five  
16 years old, the preliminary rating for opportunity  
17 for improvement was listed as Insufficient, even  
18 though the data that they did provide suggested  
19 that there was significant evidence for a gap and  
20 that this could be opportunity for improvement  
21 and be used for that.

22 CHAIR MORRISON: Arif, anything from

1       you on this one? Open for discussion.

2       Christine?

3                   MEMBER RITCHIE: I'm just looking at  
4       the screen, but it looks like the Developers  
5       provided updated information?

6                   MEMBER CASS: What's that?

7                   MR. WENGER: There were two studies  
8       that had not been completed when we previously  
9       submitted this Measure.

10                  CHAIR MORRISON: I'm sorry, Neil, so  
11       you're talking about the two studies on, the  
12       Hanson study and the Walling's study of 2013?

13                  MR. WENGER: Correct.

14                  CHAIR MORRISON: Great. Yes, so I  
15       think that's -- for the Committee, that's on the  
16       screen in front of you. The Hanson study found  
17       was 250 seriously ill people. The Walling's  
18       study was a sample of vets with advanced cancer.  
19       And, again, showing 44 percent in the first study  
20       and then a rate of 52 percent in outpatients and  
21       71 percent in inpatients, which I think would  
22       suggest that there is a gap.

1                   MEMBER CASS: I think our work group  
2 felt that there was strong evidence for a gap,  
3 that the problem was that the data was considered  
4 to be somewhat old.

5                   CHAIR MORRISON: Yes, and I think what  
6 you're hearing, Cleanne, is that they've provided  
7 updated data from 2012 and 2013, which are only  
8 four and three years old.

9                   MEMBER CASS: Okay.

10                  MS. JOHNSON: So, apologies if I  
11 confused you guys on how we did this preliminary  
12 analysis. The initial submission had several  
13 other things that they put in there. The two new  
14 things were the Hanson and the Walling's papers.  
15 But because the data were from 2007 and 2008, we  
16 still considered it to be older data, even though  
17 the publication dates are newer.

18                  MEMBER CASS: But the study itself was  
19 from 2012?

20                  CHAIR MORRISON: This is the --

21                  MR. WENGER: The study --

22                  CHAIR MORRISON: I'm sorry, Neil. This

1 is the issue of publication lag, that they're  
2 working on data that was older, but the  
3 publication lag is 2012, 2013, and I think the  
4 Committee has to weigh how recent that actually  
5 is.

6 MEMBER CASS: So, this is included as  
7 well in the CMS hospice reporting program and  
8 collected through the Hospice Item Set. So, do  
9 any members of the Committee know any of the  
10 current performance rate in the hospice setting  
11 that would be helpful in terms of determining  
12 gaps? I think this is a Measure that's widely  
13 utilized in the Hospice Item Set. I know in our  
14 hospice, we rate about 100 percent on this,  
15 because we measure it very carefully, it's easy  
16 to use and it's feasible, so it's measured. But  
17 I haven't seen the data across the board.

18 MEMBER TATUM: I guess the other way to  
19 say that is, although the data is a little bit  
20 old, 2010 is not that bad, I can't say there's a  
21 lot of data that the gap's improved by any means.

22 CHAIR MORRISON: Christine?



1                   MEMBER RITCHIE: Just a brief comment  
2                   that the denominator for our Measure is cancer  
3                   patients and not hospice patients.

4                   CHAIR MORRISON: Do I have any other  
5                   comments on Performance Gap before we move to a  
6                   vote? Can we move to a vote?

7                   MR. TILLY: To vote on Performance Gap,  
8                   select 1 for High, 2 for Moderate, 3 for Low, and  
9                   4 for Insufficient. Okay. The results are two  
10                  voting High, 15 voting Moderate, two voting Low,  
11                  and five voting Insufficient. The Measure passes  
12                  Performance Gap.

13                  CHAIR MORRISON: Cleanne, you want to  
14                  move on?

15                  MEMBER CASS: Yes. Moving on to  
16                  Reliability, the data source for this is paper  
17                  medical records. And looking at the  
18                  specifications, the denominator includes  
19                  vulnerable adults who are older than 17 years and  
20                  who have been prescribed an opioid in an  
21                  outpatient, hospital inpatient, or hospice  
22                  patient. The work group looked at the

1 denominator utilizing the term vulnerable  
2 patients and the definition given to us is for  
3 what vulnerable patients include.

4 So a vulnerable patient is one that's  
5 75 years of age or older, they score greater than  
6 2 on the Vulnerable Elder Survey 2013, life  
7 expectancy less than six months, stage four  
8 cancer, or receiving hospice care. The work  
9 group had some concerns with the denominator  
10 based on, number one, the term vulnerable is  
11 sometimes used in other contexts in other  
12 settings and could cause confusion, and then that  
13 perhaps the denominator excludes certain groups  
14 of individuals. And that it would be helpful if  
15 the denominator could be palliative care patients  
16 or, with the stage four cancer, if it could  
17 include all patients with cancer. So we wanted  
18 to open that up for discussion with the  
19 Committee.

20 CHAIR MORRISON: I'm sorry, before you  
21 go, I keep -- Arif, do you have other?

22 MEMBER KAMAL: So this is where the

1 inter-rater reliability seems impressively high  
2 for what I think if I were abstracting these  
3 charts would be difficult to find. For example,  
4 prognostication in arrears, as oncologists, we  
5 just don't document that very well at all, so it  
6 would be a challenge from an extractor point of  
7 view to understand who sort of fits in the  
8 denominator. If you presume empirically that you  
9 know the answer, then I think the numerator has a  
10 high kappa. I mean, I think you can figure out  
11 that part. It's just the denominator, which has  
12 come up in our calls, was, gosh, in arrears, this  
13 is somewhat complex to understand.

14 MEMBER CASS: Yes.

15 MEMBER KAMAL: And especially the  
16 Vulnerable Elders Survey, I mean, I'm not a  
17 geriatrician, I know others are. I don't know  
18 how often that's used in clinical practice or an  
19 extraction of other things. I know for ACO  
20 Measures, the vulnerable elder verbiage is used  
21 quite frequently, so it must be a really well  
22 accepted respected thing, I just don't know it.

1 From an extractive perspective, is that an easy  
2 thing that you can teach an extractor to find  
3 from structured and unstructured data in an EHR?  
4 I just don't know, I'm asking.

5 CHAIR MORRISON: Neil, this sounds like  
6 something for you guys to answer over at RAND.  
7 Can you help the Committee, both in terms of the  
8 denominator and the ease of identifying the  
9 denominator and the extraction ease? Because I  
10 think this was done in some of your original  
11 development work.

12 MR. WENGER: Correct, Sean. So, the  
13 definition of vulnerable, you don't need to have  
14 all of the criteria, it's any of those criteria.  
15 So, we had very little difficulty identifying  
16 stage four cancer patients or patients that have  
17 poor prognosis and terminal illness, because  
18 there's specific verbiage that was used to  
19 identify such cases. The Vulnerable Elder Survey  
20 is only used in selected places, though I have to  
21 say that it's used in dozens and dozens, maybe  
22 hundreds, of different places to identify

1 vulnerable individuals, but it certainly would  
2 not be available everywhere. And then patients  
3 receiving hospice care. So, identifying the  
4 sample can be done reliably, and that's been  
5 shown in numerous studies, but the criticism that  
6 it excludes cases that perhaps should be within  
7 this Measure is a fair criticism.

8 MEMBER CASS: So, the work group  
9 wondered if the stage four cancer could just be  
10 all patients with cancer? And --

11 CHAIR MORRISON: I hear you, Cleanne,  
12 I don't think that --

13 MEMBER CASS: I know --

14 CHAIR MORRISON: -- we can rewrite the  
15 specs. Much as on many of these we would like  
16 to.

17 MEMBER CASS: Thank you. The other  
18 concern we had, just for RAND, was about the  
19 exclusions. Excluding non-hospice patients who  
20 are already taking an opioid at the time of the  
21 measurement period opioid prescription, whether  
22 the exclusion was valid or if, again, that could

1 be a group that could be measured with this,  
2 could also be included in this Measure? That's  
3 another question for the RAND.

4 MR. WENGER: I can explain to you why  
5 we excluded that group. And it's because we  
6 didn't feel confident that we could identify  
7 cases where a patient did not need a bowel  
8 regimen. When we develop these Measures, we want  
9 them to be clinically accurate. And if one was  
10 already taking an opioid at the time and they  
11 were a non-hospice patient, we thought -- in  
12 fact, we were able to prove that outside of the  
13 range of the chart extraction, you could be  
14 missing exclusions. And we were unwilling to  
15 allow for missed exclusions. What this does is  
16 limit the sample, but it makes it more likely  
17 that you're not incorrectly dinging docs for not  
18 using a bowel regimen.

19 MEMBER CASS: Okay. Thank you. So,  
20 the reliability testing is high, because the  
21 kappa value, again, related to the numerator, is  
22 like 86 percent. And three reliability studies

1 were presented and there was very good inter-  
2 rater reliability provided. So the guidance from  
3 the reliability algorithm was that there was a  
4 Moderate degree of reliability.

5 CHAIR MORRISON: Amy, do you have --

6 MEMBER BERMAN: I have a clarifying  
7 question. So --

8 CHAIR MORRISON: Amy, I'm sorry, could  
9 you speak into the mic?

10 MEMBER BERMAN: Yes.

11 CHAIR MORRISON: Or use your outside  
12 voice?

13 MEMBER BERMAN: I'm sorry.

14 (Laughter.)

15 MEMBER BERMAN: So, I'm just wondering,  
16 in the world of oncology, how likely is it and  
17 has anybody seen the data on whether or not  
18 people are restaged? So, the question is, if  
19 they were diagnosed, for example, at stage one,  
20 do they actually restage along the way and say  
21 that somebody is stage four? And my question  
22 goes to this denominator issue, whether or not we

1       could potentially be missing large swaths of  
2       individuals who we intend to measure that  
3       potentially would be unknowingly excluded if in  
4       fact we either do not restage or don't document  
5       the restaging. Question.

6               MR. WENGER: Is that a question  
7       directed at RAND?

8               CHAIR MORRISON: Why not, Neil, go for  
9       it.

10              MR. WENGER: I would say that that is  
11       likely to be a problem, but we did not find it to  
12       be a big problem. We do not look specifically  
13       for the words stage four cancer, in fact, we  
14       almost never look for specific words. We have  
15       definitions of stage four cancer and are able to  
16       apply those definitions across the board. In  
17       fact, we use this Measure here, it's part of our  
18       measurement set, and stage four cancer is  
19       programmed using natural language processing into  
20       our EHR.

21              CHAIR MORRISON: Amy, you want to  
22       follow up? And then I've got Laura.



1                   MEMBER BERMAN: But if I understand  
2 correctly, the data that you're relying on is  
3 record abstraction, so --

4                   MR. WENGER: It is.

5                   MEMBER BERMAN: -- you are looking at  
6 people who have in some way conveyed stage four  
7 and my question goes to, do doctors restage? Has  
8 anybody looked at the data on that, because I'm  
9 hearing about this, but I have not looked at the  
10 data, so I'm asking this esteemed body, and if  
11 they are not necessarily restaging, are we  
12 potentially missing a large swath of people?  
13 That's the question. If they are showing up in  
14 your record review, I mean, you have your own  
15 selection bias in that you're using natural  
16 language that identifies people who did. I'm  
17 asking about those who don't.

18                  MR. WENGER: Right. No, I'm referring  
19 -- the natural language processing is the stuff  
20 of today, right? But in all the studies that  
21 you're looking at, stage four is identified, but  
22 not by requiring the words stage four.

1 CHAIR MORRISON: Laura, and I may have  
2 an answer to that one, Amy, afterwards, why don't  
3 we go to Laura first?

4 MEMBER PORTER: What about using the  
5 word metastatic instead of stage four? And I  
6 don't know -- I know that this is an issue that's  
7 come up for us at the Colon Cancer Alliance about  
8 whether or not people, when they're diagnosed  
9 with stage two and then they recur, are they  
10 restaged? And from what we've seen, they're not.  
11 So, they're stage two with a recurrence.

12 CHAIR MORRISON: So, let me -- Arif,  
13 and then I have a question for Neil. Okay. So,  
14 Neil, my understanding, because having gone  
15 through this with you before, is stage four is in  
16 the specs, but in the actual guidance, there are  
17 a number of other terms that identify somebody  
18 with stage four cancer. Is that not correct?

19 MR. WENGER: That is correct.

20 CHAIR MORRISON: So that this is -- in  
21 terms of defining the population, it is stage  
22 four cancer. In terms of operationalizing this

1 Measure in real time, there are a number of  
2 synonyms that have been used in the description  
3 of the Measure that identify people with stage  
4 four cancer. Is that a fair summary, Neil?

5 MR. WENGER: Yes, that's accurate.

6 MEMBER CASS: So, the reliability  
7 algorithm recommended a Moderate rating.

8 CHAIR MORRISON: So this is -- if there  
9 is no change in the evidence since this was  
10 initially examined, again, the Committee has the  
11 option just to move forward without a vote, given  
12 that this has been voted on before by the prior  
13 Committee and it was endorsed. And, Arif, I  
14 think you still -- do you have a comment? I just  
15 couldn't tell.

16 MEMBER KAMAL: I do. And I applaud  
17 RAND for having such great data on inter-rater  
18 reliability. I'm just internally struggling  
19 with, if we were all presented with a 55 year old  
20 with an ejection fraction of 15 to 20 percent,  
21 whether we would have consensus within this room  
22 of whether their prognosis is less than six

1 months and thus meets the denominator for the  
2 criteria or not. Right. I ask that question.  
3 And if we applied CMS hospice eligibility  
4 criteria to this patient, then we would need a  
5 lot more information than what may be found in --  
6 I mean, you would need sort of a medical director  
7 to review that, right, that goes one step above  
8 extraction. So, I say, one, I applaud the fact  
9 that there is such great reliability data, while  
10 at the same time saying, gosh, if I was  
11 extracting these charts, I know I would have some  
12 trouble.

13 CHAIR MORRISON: So, I'm back to my  
14 question. Is there an objection to moving  
15 forward without a vote? Or would people like to  
16 vote?

17 MEMBER SCHWIMMER: I think we should  
18 vote.

19 CHAIR MORRISON: A vote? Okay. So,  
20 we're going to vote on reliability of the  
21 evidence.

22 MR. TILLY: All right. So, this is

1 another one of these particular slides where  
2 because only data elements were tested for  
3 reliability, there are three options. So, 1 for  
4 Moderate, 2 for Low, and 3 for Insufficient. So,  
5 again, there's no High option. Okay. And the  
6 results are 18 voting Moderate, four voting Low,  
7 and two voting Insufficient. So the Measure  
8 passes Reliability.

9 MEMBER CASS: Okay. Moving on to  
10 Validity. There was face validity testing only  
11 and there were no threats to the validity  
12 reported, no risk adjustment, and again, there  
13 was a concern about the validity testing having  
14 the face validity only and whether the data had  
15 all been approved or been provided as to whether  
16 or not the mechanisms and the methodology for the  
17 face validity testing. But I believe that's all  
18 been supplied to us now, is that correct? Okay.  
19 So, the Committee initially had said Insufficient  
20 because of that lack of information, but the work  
21 group felt that if that information was supplied,  
22 it would go to a Moderate.

1 CHAIR MORRISON: Arif, things to add?  
2 Amy, are you up for a discussion or are you just  
3 a remnant from the last time? She was looking at  
4 me --

5 MEMBER SANDERS: Which Amy?

6 CHAIR MORRISON: -- like I was crazy.  
7 No, I'm sorry, Amy Berman.

8 (Laughter.)

9 CHAIR MORRISON: I'll take your  
10 comments if you want, Amy.

11 MEMBER SANDERS: No, I'm good.

12 CHAIR MORRISON: Okay. Others? Vote,  
13 Jean-Luc. Let's do it.

14 MR. TILLY: Okay. And once again,  
15 since there's face validity only, there are just  
16 the three options, 1 for Moderate, 2 for Low, and  
17 3 for Insufficient. Okay. And the results are  
18 three for Moderate -- I'm sorry, 17 for Moderate,  
19 three for Low, and four for Insufficient. So the  
20 Measure passes Validity.

21 MEMBER CASS: So, when it comes to  
22 Feasibility, several pieces of information were

1 provided. One was that while this data in this  
2 particular study was paper data extraction, the  
3 work group felt that this data could probably be  
4 easily extracted from the electronic medical  
5 record or the EHR, and wondered what the opinion  
6 of the Committee would be with that in that  
7 regard.

8 CHAIR MORRISON: Arif? Committee? Let  
9 me ask the Measure Developer. Neil, possibility  
10 of having this electronically extracted rather  
11 than paper and is this something that you guys  
12 are doing?

13 MR. WENGER: So, I have two answers to  
14 that. One is that it is indeed extractable, and  
15 in fact, in one of the studies, it was done  
16 electronically. The problem is that the  
17 exclusions are not yet available electronically  
18 until we get the EHR manufacturers to code them  
19 in.

20 MEMBER CASS: Well, I wonder what the  
21 Committee -- how much of a burden or a barrier  
22 that becomes when there's so much increasing use

1 of the electronic medical record then? If it's a  
2 threat to feasibility?

3 MEMBER RITCHIE: I think that issue is  
4 probably relevant to every single Measure that  
5 we're talking about today. And I'm not sure we  
6 have a good answer.

7 MEMBER CASS: Okay. Thank you. So,  
8 the guidance from the algorithm was Moderate on  
9 the Feasibility.

10 CHAIR MORRISON: People comfortable  
11 going to a vote? Jean-Luc?

12 MR. TILLY: All right. To vote on  
13 Feasibility, select 1 for High, 2 for Moderate, 3  
14 for Low, and 4 for Insufficient. Okay. The  
15 results are zero for High, 24 for Moderate, zero  
16 for Low, and zero for Insufficient. So the  
17 Measure passes Feasibility.

18 MEMBER CASS: So, on usability, this  
19 Measure is already part of the Hospice Item Set  
20 and it's been recommended for use in the PQRS and  
21 other data sources. So it's already being used  
22 in a number of accountability programs. It's not



1 being publically reported, but the usability  
2 seems to be very high and it's already in place.

3 CHAIR MORRISON: Dr. Kamal? Any  
4 questions from the Committee? Jean-Luc?

5 MR. TILLY: All right. So the polling  
6 is now open for Usability and Use. Select 1 for  
7 High, 2 for Moderate, 3 for Low, and 4 for  
8 Insufficient Information. And the results are  
9 three voting High, 20 voting Moderate, and one  
10 votimeasure passes Usability and Use.

11 CHAIR MORRISON: Okay. We go to the  
12 overall election.

13 MR. TILLY: To vote for overall  
14 suitability for endorsement, select 1 for Yes and  
15 2 for No. The results are 24 voting Yes and  
16 zeromeasure is recommended for endorsement.

17 CHAIR MORRISON: Well done, folks.  
18 Nicely done. So, we're going to go on to the  
19 next RAND Measure, which is 1625, Hospitalized  
20 Patients Who Die an Expected Death with an ICD  
21 that Has Been Deactivated. Again, let me turn  
22 things over to Neil first, just for a quick

1 introduction to this Measure.

2 MR. WENGER: Measure became important  
3 at the time that the ICDs were becoming  
4 prevalent. And some early, several reports,  
5 mostly case reports and series of cases,  
6 demonstrated that they were not being turned off,  
7 leading to suboptimal deaths. That was the  
8 measure, and we developed it and tested it in  
9 only a small number of patients. I have since  
10 been told that it's being used elsewhere, though  
11 we were unable to find other published data  
12 concerning further use.

13 CHAIR MORRISON: Thanks, Neil. And I  
14 have the Cass-Kamal team again. Were you guys  
15 doing the same order?

16 MEMBER CASS: Yes, he's doing it.

17 CHAIR MORRISON: He's doing it?

18 MEMBER CASS: He's doing it.

19 CHAIR MORRISON: All right. Arif,  
20 you're up.

21 MEMBER KAMAL: Okay.

22 CHAIR MORRISON: All right. Evidence,

1       sorry.

2                   MEMBER KAMAL:   All right.   So, yes.

3       So this measure regarding deactivation of an ICD  
4       when death is known for patients in the hospital.  
5       This is using paper medical records at the  
6       facility level.   And so, from the evidence  
7       perspective, it's mostly highly reliant on one  
8       systematic review and several clinical practice  
9       guideline statements.   And kudos to the NQF staff  
10      for updating at the bottom of that page the Heart  
11      Rhythm Society and others who have as consensus  
12      said that this is an important clinical issue to  
13      address.   And despite not having much empiric  
14      evidence for it, but a lot of clinical support  
15      from various groups, cardiologists and palliative  
16      care and so on, this was given a Moderate rating  
17      for preliminary evidence.

18                   CHAIR MORRISON:   Cleanne, anything to  
19      add?

20                   MEMBER CASS:   No, I'm good with that.  
21      I think that there's a good bit of information  
22      here that supports the evidence for the

1 importance of measuring.

2 CHAIR MORRISON: Open for discussion.

3 Jean-Luc?

4 MR. TILLY: Okay. To vote for  
5 Evidence for 1625, select 1 for High, 2 for  
6 Moderate, 3 for Low, and 4 for Insufficient. I  
7 think we also need just one more in the room, so  
8 if you all could, I'm sorry, but just try and  
9 vote again? Okay. The results are two voting  
10 High, 22 voting Moderate, zero voting Low, and  
11 zero voting Insufficient. So the measure passes  
12 evidence.

13 CHAIR MORRISON: Gaps, Arif?

14 MEMBER KAMAL: So, this will be a  
15 common theme through a couple of the next  
16 sections. There's not yet a lot of robust data  
17 on ICDs in place that are stopped for  
18 hospitalized patients. So the developers submit  
19 two studies. The first one of over 700 patients,  
20 veterans with advanced cancer, where really there  
21 was only an N of one that was sort of eligible  
22 for the Measure. And then the second study of

1 close to 500 patients who died in the hospital,  
2 there were 12 who were eligible for the measure  
3 and three where the ICD was deactivated. So this  
4 was given a rating of insufficient evidence, but  
5 overall, I think it actually highlights that we  
6 just don't have a lot of data yet with these  
7 experiences.

8 MEMBER CASS: Yes.

9 CHAIR MORRISON: Cleanne, comments,  
10 thoughts?

11 MEMBER CASS: No, I'm --

12 CHAIR MORRISON: Christine?

13 MEMBER CASS: -- I would agree.

14 CHAIR MORRISON: Discussion from the  
15 Committee?

16 MEMBER HANDZO: Just to -- oh, I'm  
17 sorry. Christine, between us, Christine and I  
18 had it right, she can't put hers down and I can't  
19 put mine up. Just to review, Karen, if we vote  
20 insufficient on this, the measure is dead, yes?

21 MS. JOHNSON: Right.

22 CHAIR MORRISON: Yes, Debra?

1                   MEMBER WIEGAND: So I'm having angst  
2 about this because I do work in cardiology and I  
3 know this is a really important issue. And I  
4 just presented last week on this topic and people  
5 came up to me and said, oh, the ICDs are not  
6 being shut off at end of life. So, I'm kind of  
7 struggling with, there's a problem here, but we  
8 don't have reliable data, so what do we do with  
9 that?

10                  MEMBER CASS: One of the things that  
11 I've wondered about and was going to hold this  
12 comment until further on in this discussion, do  
13 we ever recommend that measures go to another  
14 panel, like cardiology? There's no crossover  
15 here? Because it seems like it's the  
16 cardiologists that need to be measuring this.

17                  MS. JOHNSON: People can ask for  
18 measures to go to different projects, but we slot  
19 things in for different reasons.

20                  MEMBER CASS: I'm sure.

21                  MS. JOHNSON: So, this felt like an  
22 end of life --

1                   MEMBER CASS: It's just the off the  
2 wall comment, because if they would be having  
3 that discussion at the time that they're  
4 implanted, it would be much easier for us that  
5 are helping them to journey on, having them  
6 turned off. It's hard to know when that end  
7 point is.

8                   CHAIR MORRISON: Christine?

9                   MEMBER RITCHIE: So, Karen, this does  
10 not count as an evidence with exception? No  
11 evidence with exception?

12                  MS. JOHNSON: No, that only fits with  
13 the evidence sub-criterion. So we're talking  
14 about the opportunity for improvement criterion.

15                  MEMBER RITCHIE: Okay.

16                  MS. JOHNSON: Yes.

17                  CHAIR MORRISON: So, I've got Woody  
18 and then I've got Paul.

19                  MEMBER MOSS: So, I'm really confused.  
20 This is a maintenance measure, which means it  
21 somehow survived the light of day three years  
22 ago, four years ago, and now we're looking at it

1 and there's insufficient evidence. So it  
2 shouldn't have died in 2012, how is it still  
3 alive for us to be reviewing it?

4 MS. JOHNSON: I think that data were  
5 sufficiently recent four or five years ago when  
6 they looked at it. Right now, this data is from  
7 2008, 2005, so it's getting old. So, again, the  
8 reason that we selected insufficient is just, we  
9 don't have more current data in front of us.  
10 Five years ago, this data wasn't old, right?  
11 Does that make sense?

12 CHAIR MORRISON: Neil, I know you're  
13 not in the room, but I hear an mm-hmm as if  
14 you're trying to get a word in.

15 MEMBER TATUM: I think that was me --

16 CHAIR MORRISON: Oh, sorry.

17 MEMBER TATUM: -- and I didn't have --

18 CHAIR MORRISON: What was that?

19 MEMBER TATUM: It was me and I didn't  
20 have the floor, so I stopped myself. I was next  
21 in line, but --

22 CHAIR MORRISON: Paul, you're next in



1 line, and then I've got Amy.

2 MEMBER TATUM: I'd like to make the  
3 case that this is important enough and, while  
4 it's marked as insufficient, our task is to see  
5 if there's a gap. And lack of evidence of a  
6 change doesn't mean that this isn't still a gap.  
7 And you have one system in which a single person  
8 had the defibrillator deactivated and you have  
9 another system in which 25 percent had a  
10 defibrillator deactivated. So that seems like a  
11 gap to me, and I don't know the fact that the  
12 evidence isn't updated is so much that we should  
13 throw this measure out because I'd make the case  
14 there's evidence for gap there.

15 CHAIR MORRISON: Amy, then Karl.

16 MEMBER BERMAN: I'm using my louder  
17 voice. So, for those who aren't familiar with  
18 what this really means, if somebody has an  
19 implanted cardio-defibrillator and they are known  
20 to be progressing toward death, death is  
21 imminent, and they don't have a magnet put on  
22 their chest and it isn't shut off, they go

1 through the most violent of deaths, being shocked  
2 repeatedly through the entire death process,  
3 oftentimes in front of their family. So, there's  
4 a tremendous amount of suffering and a tremendous  
5 amount of grief and other kinds of stress as a  
6 result.

7 So, the question, I guess, this kind  
8 of goes to the, while it is a rare occurrence,  
9 this essentially is, I guess, what you would call  
10 a sentinel event. This is the kind of thing that  
11 is an absolute. And I'm wondering, even though  
12 we have issues with the small data or the time  
13 line of the data, but it is in current use, how  
14 we might think about this as a group when we know  
15 something is so wrong and has been considered the  
16 standard and we know that today this still  
17 commonly goes on, how we might be able to address  
18 this as a group? This is one of those kinds of  
19 things.

20 CHAIR MORRISON: Karl?

21 MEMBER STEINBERG: Yes. Just real  
22 briefly, because I'm saying the same thing

1 everyone else has just been saying, but even if  
2 this happens on a pretty infrequent basis, it's a  
3 pretty horrible thing to happen. We have enough  
4 evidence just anecdotally that this still  
5 happens, to me that is enough to give it a  
6 moderate.

7 CHAIR MORRISON: Gregg?

8 MEMBER VANDEKIEFT: Clarifying  
9 question for Karen, and you may have already said  
10 this and I missed it and if so, I apologize,  
11 which is, where do we draw the line in terms of  
12 the currency of data to call it adequate? I  
13 mean, clearly there was a gap and as Paul pointed  
14 out, we haven't seen evidence that that gap has  
15 been closed. Is there a time line where you say,  
16 anything before such and such, we can't use?

17 MS. JOHNSON: No, unfortunately not.  
18 Again, NQF pretty much doesn't give absolutes on  
19 many things like that, so, no. I think what you  
20 have to think about here is you will have, in  
21 some cases, your own personal knowledge of what  
22 may or may not be going on, and you can

1 extrapolate if you want to and say, well, we know  
2 this was happening five or six years ago, do I  
3 have any evidence that it's changed or that it  
4 hasn't changed? And you answer in that way.

5 CHAIR MORRISON: So, let me just  
6 summarize the discussion and then I think we can  
7 go to a vote. And I just, I want to have the  
8 opportunity for a different opinion. So, what  
9 I've heard, and nobody has contradicted it, from  
10 Amy Berman, is that many people view the failure  
11 to deactivate an ICD prior to an expected death  
12 as close to a never event as possible. That the  
13 most recent data we have come from 2005, 2006,  
14 that demonstrate that 25 percent of people who  
15 were eligible to have their ICD deactivated had  
16 their ICD deactivated, which means that 75  
17 percent did not. Which is a long way from Amy's  
18 one percent.

19 Before we move to a vote, I just want  
20 to make sure that nobody in the room with that  
21 level of knowledge strongly disagrees with Amy's  
22 statement, because that obviously would make a

1 big impact on how you view the data, and whether  
2 anybody is aware of more recent studies that have  
3 a different prevalence rate. And I'm going to  
4 ask -- I just wanted to put those two questions  
5 out before we move to thinking about this,  
6 because what I'm hearing or looking around is  
7 sort of a different view from where the NQF staff  
8 came down, and I just want to make sure that that  
9 was sort of cleared away on the table when people  
10 go to vote. Jean-Luc?

11 MR. TILLY: Okay. To vote on  
12 Performance Gap, select 1 for High, 2 for  
13 Moderate, 3 for Low, or 4 for Insufficient. And,  
14 Amy, I'm sorry, if you could just text me your  
15 vote?

16 MEMBER SANDERS: I did text you my  
17 vote.

18 CHAIR MORRISON: It's in the cloud  
19 somewhere, Amy.

20 MR. TILLY: That's right. It's making  
21 its way down here, maybe just one more time just  
22 so we're sure.

1                   MEMBER SANDERS: I texted it, but I  
2 did it again.

3                   MS. ROILAND: Amy, can you just put it  
4 in the chat box? It doesn't seem to be sending  
5 through text. Sorry about that.

6                   CHAIR MORRISON: Yes?

7                   MEMBER MOSS: While we're waiting --

8                   CHAIR MORRISON: Sure.

9                   MEMBER MOSS: -- so I just started  
10 literature searching and I found a study, Nathan  
11 Goldstein, Jean Kutner, from 2010 looking at 900  
12 hospices, 58 percent reported a patient had been  
13 shocked with a non-deactivated ICD. I don't know  
14 if that's more data or not.

15                  CHAIR MORRISON: It is more data.  
16 That's not -- it's a slightly different  
17 population, but one you would expect, and I think  
18 my name is on that paper, embarrassingly enough.

19                  MR. WENGER: Right. Actually, we were  
20 aware of Jean's paper and I guess Sean's paper.

21                  CHAIR MORRISON: It's called Young  
22 Onset Dementia.

1 MR. WENGER: But we didn't think it  
2 applied here. But I would love for someone to  
3 find a paper that we couldn't.

4 CHAIR MORRISON: I'm sorry, Neil,  
5 you've got to use your outdoor voice, we can't  
6 hear you.

7 MR. WENGER: Oh, sorry. We were aware  
8 of that paper, but didn't think that it applied  
9 to this population. But would welcome someone  
10 finding a paper that we were unaware of.

11 MR. TILLY: Okay. So, the results are  
12 one voting High, 23 voting Moderate, zero voting  
13 Low, and zero voting Insufficient. The Measure  
14 passes Performance Gap.

15 CHAIR MORRISON: Arif, you want to  
16 move us along?

17 MEMBER KAMAL: All right. So, under  
18 Reliability, so this is abstracted through paper  
19 medical records for, under specifications,  
20 patients who have been in the hospital for at  
21 least three days who then have an expected death.  
22 And you can see the criteria there, essentially

1 receiving comfort care, receiving hospice care,  
2 which I presume means inpatient hospice care, had  
3 a life threatening disease or expected to die.  
4 And the reliability testing, the inter-rater  
5 reliability testing, essentially they took ten  
6 percent of the 496 sample, the one that had 12  
7 with an ICD in it, and with some bad luck, the 47  
8 that they pulled, none of them had an ICD. So  
9 they couldn't calculate an inter-rater  
10 reliability test. So that led to the staff  
11 ranking it as Insufficient.

12 And from our work group, there was an  
13 open question regarding whether the death had to  
14 occur in the hospital. I presume from the  
15 abstraction methodology it must, because it says  
16 from the facility, but with the ways that  
17 hospital related deaths are calculated  
18 differently based on who you ask, like UHC, U.S.  
19 News and Report, and others record hospital death  
20 even if a patient dies in hospice, for example,  
21 it's calculated as a hospital related death if it  
22 occurs within 30 days. There's multiple



1 methodologies for calculating hospital related  
2 death, how this would fit? And I ask that to  
3 Neil or Karl, because we weren't sure exactly how  
4 to interpret.

5 MR. WENGER: So, these were all in-  
6 hospital deaths.

7 MEMBER KAMAL: Okay.

8 CHAIR MORRISON: Open for discussion.

9 MEMBER KAMAL: I think as a work  
10 group, this is where we had the most thought and  
11 cognitive dissonance around what we believed was  
12 a good measure, it just doesn't have any sort of  
13 quantifiable inter-rater reliability data yet.  
14 And, again, it harkens back to the idea that  
15 there's not a lot of patients with ICD in these  
16 samples, so it may just be reflective of that, or  
17 as a work group, we were concerned about whether  
18 there was a need to ask for or seek out more data  
19 at this time or make that a comment for the next  
20 time. And I don't think we had a conclusion  
21 about that.

22 CHAIR MORRISON: Karen, can this be a

1 comment for the next time? Can you give us some  
2 guidance on this?

3 MS. JOHNSON: It could certainly be a  
4 comment. We can try, we have varying success on  
5 this, but sometimes we try to highlight certain  
6 things when we put reports out for comment, so if  
7 somebody out there knows something that we don't  
8 know, maybe they will share it. So that might be  
9 another option. Just to see.

10 CHAIR MORRISON: Yes. Taking my  
11 Chair's hat off, I know that we will have  
12 reliability data on this in about six months.  
13 We're just finishing a large multi-site study on  
14 AICDs or ICDs and we will have good data within  
15 six months. I would be -- if the study falls --  
16 actually, it's closed for enrollment, so it's in  
17 the analog -- yes. So, I -- that would be  
18 hospitalized patients. I would be comfortable  
19 voting for this measure.

20 MEMBER CASS: It would seem like we  
21 need a measure for this one for hospice patients  
22 and palliative care, as opposed to hospitalized.

1 MS. JOHNSON: So, I'm just curious,  
2 I'm not a clinician, so I don't know the answer  
3 to this, but is it generally pretty easy to find  
4 in a medical record if you turned it off? Is  
5 this something hard to find or is it pretty  
6 clear?

7 CHAIR MORRISON: It's very, very  
8 clear. It's crystal clear.

9 MEMBER CASS: It's clear.

10 CHAIR MORRISON: Yes, it's crystal  
11 clear.

12 MEMBER CASS: It's very clear.

13 CHAIR MORRISON: Yes, I mean, I think  
14 if people are concerned, as a clinician working  
15 in a hospital, it is very, very easy to find this  
16 in the medical record. Jean-Luc?

17 MR. TILLY: Okay. To vote for  
18 reliability, please select 1 for High, 2 for  
19 Moderate, 3 for Low, 4 for Insufficient. The  
20 results are zero voting High, 22 voting Moderate,  
21 zero voting Low, and two voting Insufficient.  
22 The Measure passes Reliability.

1 CHAIR MORRISON: Arif?

2 MEMBER KAMAL: All right.

3 CHAIR MORRISON: Continue, sir.

4 MEMBER KAMAL: So on to validity. So,  
5 like would be expected, most of this is around  
6 face validity using the modified RAND  
7 methodology, using the ASSIST Expert Panel, which  
8 these measures come from the ASSIST cohort. So  
9 face validity testing was the only validity  
10 testing provided. The specific results of the  
11 testing are not provided, there's not risk  
12 adjustment, and NQF staff provided us with  
13 Insufficient, which I think we've seen before,  
14 right, face validity only as Insufficient with  
15 the group to potentially recommend it to come out  
16 of Insufficient, is that right?

17 MS. JOHNSON: This is one where the  
18 RAND group did provide that extra information  
19 about face validity, so now they have that --

20 MEMBER KAMAL: Now we have it? Okay.

21 MS. JOHNSON: -- information. Yes.

22 So now the question is just, do you have any

1 concerns about missing data or having meaningful  
2 differences? It being a rare event, the  
3 meaningful differences may not be as big a deal.

4 MEMBER KAMAL: Right.

5 CHAIR MORRISON: Questions from the  
6 Committee? Jean-Luc?

7 MR. TILLY: Okay. And this is a  
8 little bit different, so validity testing was  
9 just face validity, so there are just three  
10 options, 1 Moderate, 2 Low, and 3 Insufficient.  
11 Okay. The results are 23 voting Moderate, zero  
12 voting Low, and one voting Insufficient. So the  
13 measure passes Validity.

14 CHAIR MORRISON: Arif, on to  
15 Feasibility?

16 MEMBER KAMAL: All right. So this is  
17 really about sort of ease of -- well, sort of  
18 burden for abstraction. And the developers  
19 reported that none of the data elements are  
20 included in electronic sources, meaning that  
21 while we as a Committee have said that this would  
22 be easy to find in terms of nodes, that none of

1       that data would be structured data that we're  
2       aware of, and because of questions regarding  
3       burden and paper based manual abstraction, the  
4       staff provided us with a Low rating up front.

5               CHAIR MORRISON:   Open for discussion.  
6       Paul, I'm sorry, did you -- no, okay.

7               MEMBER CAUGHEY:   Sorry.

8               CHAIR MORRISON:   Yes, Michelle?

9               MEMBER CAUGHEY:   I just have a  
10       question. I think these -- the cardiologists are  
11       required to have a registry of these and track  
12       them very closely, so it just may not be easily  
13       abstractable in our literature, but the two data  
14       sets could be merged.

15              CHAIR MORRISON:   Christine?

16              MEMBER RITCHIE:   Yes, I'm not sure  
17       that it requires that they document that the ICD  
18       has been turned off, though. I mean, again, I  
19       think this chart abstraction business is sort of  
20       what we've been dealing with all along. And I  
21       think, to somebody else's point, this is probably  
22       easier to find in the chart than a lot of other

1 things that we're going to be looking for in the  
2 chart.

3 CHAIR MORRISON: Other people,  
4 comments, want to address -- Amy, was that you?  
5 Yes, it is.

6 MEMBER BERMAN: Forgive me, but I just  
7 want to bring into our conversation, there is a  
8 study that was published in 2012, if it is  
9 helpful for us, that has maybe a little bit more  
10 on prevalence. It's by Tajouri, it is a study of  
11 420 patients, 71 percent were male, who had the  
12 implanted cardio-defibrillator. And it talks  
13 about a third of those patients having advance  
14 directive and only two percent of the advance  
15 directives had any mention of deactivating an  
16 ICD. In other words, there is a very notable gap  
17 in that the cardiologists are not discussing the  
18 turning off of their ICD.

19 CHAIR MORRISON: Thanks. Other  
20 comments about feasibility? I mean, I think  
21 Christine has raised this issue several times and  
22 I think it is real. Are we comfortable going to

1 a vote on the feasibility? Okay.

2 MR. TILLY: Okay. To vote on  
3 Feasibility for 1625, select 1 for High, 2 for  
4 Moderate, 3 for Low, and 4 for Insufficient.  
5 And, I'm sorry, Bob, could you try sending me  
6 your vote again via text or email? All right.  
7 And the results are zero voting High, 21 voting  
8 Moderate, three voting Low, and zero voting  
9 Insufficient. The measure passes Feasibility.

10 CHAIR MORRISON: And on to our last,  
11 usability.

12 MEMBER KAMAL: All right. So  
13 usability reflects the uptake of this measure and  
14 you'll see the note that the NQF particularly  
15 looks at uptake into pay-for-performance or  
16 accountability programs within three years of NQF  
17 endorsement. And this is the story, I think, of  
18 multiple stakeholders trying to get this into  
19 pay-for-performance systems and it just hasn't  
20 gotten there yet. So, you'll see there's planned  
21 use for accountability, but not yet. One example  
22 is the California Department of Healthcare



1 Services for a publically reported dashboard,  
2 although a final decision has not been made about  
3 that.

4 And then you'll also see the comment  
5 regarding the MAP, I'm interested in what Sean  
6 has to say about that, recommending inclusion in  
7 the PQRS, as well as CAHPS being behind that.  
8 And this might fall victim to the fact that I  
9 don't think any of our NQF endorsed Measures for  
10 palliative care really move forward to PQRS, so  
11 this might have just gotten guilty by  
12 association. So it was given a Low usability  
13 score based on -- I think the major criteria of  
14 inclusion in accountability programs within three  
15 years of endorsement set the bar.

16 MS. JOHNSON: That and, again, this  
17 catch-22 that we don't have the data, so we can't  
18 show improvement over time either --

19 MEMBER KAMAL: Right.

20 MS. JOHNSON: -- which is another big  
21 piece of Usability and Use.

22 CHAIR MORRISON: So let me just take

1 my hat off because Arif asked me to. This was  
2 strongly endorsed by the MAP hospital work group.  
3 There was a lot of enthusiasm for this measure  
4 when it came before MAP and, obviously, I cannot  
5 explain the workings and mechanisms at CMS as to  
6 what happened after it went from MAP to CMS. But  
7 there was enthusiasm and, as said, very strong  
8 support, and the MAP echoed many of the comments  
9 that we've heard around the room today. I'm so  
10 sorry, Linda, go ahead.

11 MEMBER SCHWIMMER: That's all right.  
12 So, this is really a question, maybe, for the  
13 clinicians more than anyone else, because I don't  
14 know how this would work. If I was a patient  
15 that had this implant and I needed to have a  
16 conversation with someone to have it deactivated,  
17 who would know that I had that, who would  
18 initiate that conversation with me, and then, how  
19 would that and where would that be done? Because  
20 as I've been listening to the conversation, it  
21 feels like the measure doesn't necessarily align  
22 with the actions that need to be taken and then

1 would be really difficult to align with either a  
2 quality improvement program or a pay-for-  
3 performance program. And maybe it's bad luck,  
4 but maybe that's why it hasn't really either been  
5 studied the way yet we need or been implemented.  
6 So maybe somebody could kind of walk me through  
7 that. That would be helpful, thank you.

8 CHAIR MORRISON: Take a crack first,  
9 Debra, and then I'll fill in.

10 MEMBER WIEGAND: Yes, sure. So, I  
11 think it would depend on the setting, but in an  
12 acute care setting, it's usually part of the  
13 advance care planning discussion and then it goes  
14 into the advance care planning note that's in the  
15 documentation. And then you end up having the  
16 whole goals of care, do not resuscitate, they  
17 might have some leveled system, but it's usually  
18 kind of a red flag and very available to be seen.  
19 I'm not sure if that answers the question. And  
20 then if somebody is going to go from acute care  
21 to hospice, at least from my experience, this  
22 discussion happens before they leave, if

1 everything goes the way it's supposed to, so that  
2 when they go to hospice, the device is either  
3 deactivated in the hospital or they get them home  
4 and then deactivate.

5 CHAIR MORRISON: And the only thing I  
6 would add to that is that the data, at least data  
7 from our group, has shown that this is -- even  
8 though patients would like to talk, engage in  
9 advance care planning, patients with ICDs do not  
10 want to talk about this at the time of  
11 implantation. And they are very clear about  
12 that. And the question is about -- and that has  
13 come up, that came up at the MAP as to, is this  
14 an appropriate measure at this time or should it  
15 have happened a long time ago?

16 This is one of those areas where  
17 patients really do not want to have that  
18 conversation at all. And so the question that  
19 you raised is, when is the right timing about  
20 this? I think that's something that we don't  
21 know from the literature, but I would suggest  
22 that by the time somebody's heart has stopped

1 because they're dying, it's probably too late.

2 MEMBER WIEGAND: Right. And just to  
3 add one more thing, on the guidelines that are  
4 part of this document, the Heart Rhythm Society  
5 and the other cardiology guidelines, do say to  
6 have the conversation, at least an initial  
7 conversation, pre-implantation, but in actuality  
8 in clinical, it doesn't usually happen.

9 CHAIR MORRISON: As one of our  
10 patients said in our focus groups, are you crazy,  
11 why would I ever want to turn this off?

12 MEMBER SANDERS: This is Amy. I know  
13 we're not supposed to bring anecdotal data to  
14 bear, but in this one instance, I beg that you  
15 grant me an exception. In the case of my father,  
16 who had an implanted defibrillator, was in the  
17 last days of his life, was already comatose, I  
18 was a physician, granted I was only a humble  
19 intern, but it was the hospice nurse who said, oh  
20 my God, we have to turn that thing off. And to  
21 this day, 12 years later, I am grateful to that  
22 hospice nurse. So I do think that, while as

1 advanced care planning becomes more common, it  
2 may become a common feature of advanced care  
3 planning discussions, it is still appropriate at  
4 the stage of time that is specified by this  
5 measure.

6 CHAIR MORRISON: Thank you. Very  
7 helpful. Jean-Luc, I think we'll go to a vote,  
8 unless anybody objects? Okay.

9 MR. TILLY: All right, great. To vote  
10 for Usability and Use, select 1 for High, 2 for  
11 Moderate, 3 for Low, 4 for Insufficient  
12 Information.

13 CHAIR MORRISON: Cindi, I'm sorry, did  
14 you have a -- that's okay, thank you.

15 MR. TILLY: The results are four  
16 voting High, 19 voting Moderate, one voting Low.  
17 So the measure passes Usability and Use.

18 CHAIR MORRISON: All right, guys. We  
19 now go to the final vote.

20 MR. TILLY: To vote for overall  
21 suitability for endorsement to answer the  
22 question, does the measure meet NQF criteria for

1 endorsement, select 1 for Yes and 2 for No. The  
2 vote is 24 voting Yes and zero voting No. So the  
3 measure is recommended for endorsement.

4 CHAIR MORRISON: All right, guys. I'm  
5 going to actually beg your indulgence. I know  
6 we're supposed to take a break at 3:15, but Neil  
7 Wenger has been on the phone for almost two hours  
8 and we have one more of his measures to do. So,  
9 would people be okay if we just did the last RAND  
10 Measure and let Neil go back to work? And then  
11 we'll take a break at 3: 30? Yes, it's true.  
12 We'll let Neil go to lunch. And the good news  
13 is, we were over an hour behind and we've now  
14 caught up to being just 15 minutes behind. So,  
15 well done, folks. Well done. Neil, unless you  
16 want to leave, do you want to do your last  
17 measure about patients admitted to the ICU who  
18 have care preferences documented?

19 MR. WENGER: Really appreciate it,  
20 Sean, thank you. So, this measure is for people  
21 who get admitted to an ICU, for vulnerable adults  
22 who get admitted to an ICU and are there for at

1       least 48 hours that there must be documentation  
2       about the patient's preferences or documentation  
3       why it's not feasible to document about the  
4       patient's preferences.

5               CHAIR MORRISON: Thank you, Neil. And  
6       then I've got Amy Sanders and Tracy as the  
7       discussants. And I'm not sure if you guys  
8       discussed or decided how you were going to go.

9               MEMBER SANDERS: I think I was  
10       designated as the -- this is Amy Sanders. I was  
11       designated as the primary respondent and I'm  
12       ready to go in that role if that's okay with  
13       Tracy.

14              MEMBER SCHROEPFER: That's okay with  
15       me, but can I ask a clarifying question --

16              CHAIR MORRISON: Absolutely.

17              MEMBER SCHROEPFER: -- of the  
18       developer?

19              CHAIR MORRISON: Sure.

20              MEMBER SCHROEPFER: So, Neil, I just  
21       want to make sure before we start this, because  
22       we were confused when our group had our meeting.



1       So is this about the discussion? That is, if  
2       there's been a discussion about preference in  
3       terms of 48 hours? Or let's say that it's me  
4       who's in the ICU and I have an advance care plan,  
5       would that count even if nobody discussed  
6       anything with me?

7               MR. WENGER: Yes. It simply must  
8       exist, the preferences must exist. So if they  
9       preceded the admission to the ICU, maybe that's  
10      what you're getting at --

11             MEMBER SCHROEPFER: Yes.

12             MR. WENGER: -- that would count.

13             MEMBER SCHROEPFER: That would count?

14      Okay.

15             MR. WENGER: Yes.

16             MEMBER SCHROEPFER: Thank you.

17             MR. WENGER: Yes. I think you'll find  
18      for all of our measures that our goal is to make  
19      them what would be clinically appropriate under  
20      the circumstances, not to check a box.

21             MEMBER SCHROEPFER: Oh, well, that's  
22      helpful, because we really did struggle with that

1 piece. So, thank you.

2 CHAIR MORRISON: Amy, we are all  
3 sitting in rapt attention. Go ahead.

4 MEMBER SANDERS: Okay. Thank you.  
5 And I thank you also for everybody going ahead  
6 with this now, because it will allow me probably  
7 to get to the airport on time. So, this is  
8 Measure 1626, it is a maintenance measure, it is  
9 a process measure. It was originally endorsed in  
10 February of 2012. The measure assesses the  
11 percentage of vulnerable adults where care  
12 preferences are documented within 48 hours of ICU  
13 admission. During our working group call, we had  
14 a fairly in-depth discussion about definitions of  
15 terms. So, as previously, the definition of  
16 vulnerable elders, so we can consider that as --  
17 I'll stipulate that as having already been  
18 discussed.

19 There was also some question about  
20 what constitutes admission to an ICU. Is it when  
21 the patient is accepted by, say, a NICU fellow?  
22 Is it when the patient physically rolls into the

1 ICU? If there could be some comment perhaps  
2 added that would clarify that? I suspect that  
3 what is meant is that the clock starts ticking  
4 when somebody rolls into an ICU, or at least that  
5 would make sense to me, but with it not  
6 specified, I don't want to assume.

7 MR. WENGER: So, it's actually when  
8 the admission orders get written, and maybe that  
9 should be clarified.

10 MEMBER SANDERS: Okay. So then, in  
11 some cases, it may actually be, depending on how  
12 long somebody has to wait for a bed, at least in  
13 my hospital, I'm not so sure that admission  
14 orders and physical presence in the ICU are  
15 actually the same thing and they can be separated  
16 by as much as hours. In any case, as a  
17 maintenance measure, the developer did not  
18 present new evidence, but there is, I think,  
19 actually some new evidence based on my very quick  
20 literature search.

21 In particular, we're looking to gap in  
22 care. The previous evidence included a

1 systematic review without -- and the processing  
2 review. There were some questions about, is it  
3 documentation or is it actual review of the  
4 preferences? And I think actually I may have  
5 misread some of the documentation during the  
6 working group call, and if I did, I do apologize  
7 for that, because when I read it just now, it  
8 felt very different to me. So, thank you, Neil,  
9 for the clarification. And I'll stop now and see  
10 what I should do next.

11 CHAIR MORRISON: Thanks. And I'm  
12 losing my mind because I can't remember who else  
13 I had on this one. Tracy, thank you. Tracy,  
14 anything to add?

15 MEMBER SCHROEPFER: No.

16 CHAIR MORRISON: So, the floor is open  
17 for discussion on Evidence. And NQF's initial  
18 recommendation was Moderate. Jean-Luc, vote?

19 MR. TILLY: So to vote on Evidence for  
20 1626, select 1 for High, 2 for Moderate, 3 for  
21 Low, 4 for Insufficient. Okay. The results are  
22 zero voting High, 24 voting Moderate, zero voting

1 Low, and zero voting Insufficient. So the  
2 measure passes evidence.

3 CHAIR MORRISON: Amy, you want to talk  
4 to us about gaps?

5 MEMBER SANDERS: Yes, sure. So, there  
6 I believe has already been mention of the Walling  
7 2013 paper that looked at a national sample of VA  
8 patients. With respect to this measure, there  
9 was an n of 150 and there was an approximately 46  
10 percent gap in care. So, I realize that was just  
11 the VA, and I think it -- well, it was just VA  
12 patients, but I think there is a gap in care for  
13 this measure. And then, my previous comments  
14 about disparities hold here as well, that there's  
15 evidence in the literature that the very  
16 categories that define disparities are not being  
17 documented, so I'm pretty sure that this measure  
18 is not being assessed according to membership in  
19 one or another disparity group.

20 CHAIR MORRISON: Tracy, anything to  
21 add? And, I guess, a question to Karen or  
22 Rachel, this was initially by your team rated as

1 Insufficient. Can you talk to us just a little  
2 bit about the reasons for that rating?

3 MS. JOHNSON: Well, pretty much the  
4 same thing. My understanding of the 2012  
5 submission, all the data were five years or  
6 older. So it's just a matter of, we don't quite  
7 have the data. Is it still a problem, is the  
8 question in front of us.

9 CHAIR MORRISON: Open for discussion.  
10 And as Karen said, the reason for staff rating of  
11 Insufficient was, is this still a problem? And  
12 those who have evidence, rather than anecdote, it  
13 would be helpful if we heard it. Debra, I can  
14 see you're itching to say something.

15 MEMBER WIEGAND: I was struggling with  
16 my name. I don't have research evidence, but I  
17 know from a clinical perspective, it's still an  
18 issue. And there's a lot of factors behind that.

19 CHAIR MORRISON: And, Karen, just to  
20 push you guys a little bit, because I know -- one  
21 can read a lack of evidence for five years  
22 because there are no studies as, A, Insufficient,

1 or, B, it's still a problem and it continues to  
2 be a problem. And I guess my convoluted question  
3 is, are we -- is this looking at five years old  
4 data without further data, is that a strong  
5 problem for us? Or if there is clinical  
6 recognition that this is still a problem, do we  
7 have to rely on that? Some would say you don't  
8 need a randomized controlled trial to see if you  
9 throw a brick out the window that it falls.

10 MS. JOHNSON: Yes. You can rely on  
11 your experience, your own knowledge, to answer  
12 this question. This is tough, and it's tough for  
13 all of these measures, because they're not being  
14 used and it's not easy to get the data. It was  
15 not easy for us on some of these to put that X on  
16 those boxes. But you guys just have to weigh  
17 what you're willing -- if you feel like there's  
18 still a gap, then you should vote accordingly.

19 CHAIR MORRISON: If people are  
20 comfortable going to a vote -- sorry, Paul, you  
21 put your -- fair enough. Jean-Luc?

22 MR. TILLY: For the actual public

1 record -- please vote for Performance Gap, select  
2 1 for High, 2 for Moderate, 3 for Low, and 4 for  
3 Insufficient.

4 MEMBER SCHROEPFER: I found a study,  
5 but I guess it's too late? Sorry.

6 MR. TILLY: And the voting is, one  
7 voting for High, 22 for Moderate, zero for Low,  
8 and one for Insufficient. So the measure passes  
9 Performance Gap.

10 CHAIR MORRISON: Amy, you want to talk  
11 to us about Reliability?

12 MEMBER SANDERS: Sure. And I want to  
13 start just by, and I apologize in advance, but I  
14 want to revisit the issue of what precisely in  
15 terms of documentation satisfies this measure.  
16 Because I believe I heard Neil said that the mere  
17 existence of advance directives of a POLST or a  
18 MOLST or whatever, in the chart, is sufficient,  
19 but I direct your attention to Page 3 of the sort  
20 of master document, where it says, documentation  
21 of having an advance directive, other advance  
22 care planning document, or POLST in the medical



1 record is not sufficient to be counted in the  
2 numerator. There it's against the -- this is a  
3 distinction to the 48 hour requirement, there's  
4 an and for the 48 hour requirement.

5 But on Page 17, it also says, simply  
6 having an advance directive or other advance care  
7 planning document in the medical records does not  
8 satisfy the criterion. However, a notation in  
9 the record during the allotted time period  
10 referring to preferences or decisions within such  
11 document does satisfy the requirement. So, it  
12 seems to me that there has to be some reference  
13 within 48 hours of ICU admission to discussion,  
14 determination, confirmation, affirmation,  
15 reviewing with a proxy, that somehow the  
16 decisions about the -- care plans were reviewed  
17 with a human being, not just a chart.

18 CHAIR MORRISON: Neil, can you tackle  
19 that one before we go to the group discussion?

20 MR. WENGER: Yes. I was actually  
21 referring to documentation that existed during  
22 the admission that was prior to the ICU

1 admission, not simply having an advance directive  
2 in the record. Which these days, the advance  
3 directive may very well have been from a prior  
4 admission or even in the outpatient setting.

5 MEMBER SANDERS: Or many years old.

6 MR. WENGER: Right. But that there  
7 needed to be documentation, but that it didn't  
8 need to occur during that 48 hour period, is what  
9 I was referring to.

10 MEMBER SANDERS: Okay. I'm not -- how  
11 does that square against the statement on Page 3,  
12 i.e. the 48-hour time frame also must be  
13 satisfied?

14 MS. JOHNSON: So, Neil, this is Karen  
15 at NQF, let me help you out there. That was my  
16 wording and perhaps that is confusing. I think  
17 what I was trying to get across is that, the  
18 documentation, something has to be written, and  
19 if I'm understanding it correctly, Neil,  
20 something has to be written within that 48 hours,  
21 that discussion or whatever has to happen within  
22 that 48 hours. It sounds like what you're saying

1 is that the advance directive or whatever could  
2 have been done earlier, but still within the 48  
3 hours, you need to have that discussion. Is that  
4 a correct --

5 MR. WENGER: No. The --

6 MS. JOHNSON: -- interpretation?

7 MR. WENGER: No. The way that we  
8 implemented this is that there needed to be  
9 documentation about preferences that occurred  
10 during the hospitalization and you had up to the  
11 first 48 hours in the ICU. And in fact, you  
12 needed to be in the ICU for 48 hours to even  
13 qualify for this measure. Most of the  
14 documentation was indeed in the ICU and almost  
15 everyone satisfied it that passed it, with  
16 documentation in the ICU. But it is true that  
17 simply having an advance directive in the record  
18 would not satisfy this measure.

19 MEMBER SANDERS: So, the ICU team needs  
20 to speak either to the patient or the patient's  
21 proxy to sort of review their wishes upon  
22 admission to the ICU. Is that an accurate --

1 MR. WENGER: I think data in the record  
2 beyond that would be acceptable. So, that would  
3 certainly satisfy it. But the documentation  
4 didn't necessarily need to come from the ICU  
5 team, it could be from a continuity doc, it could  
6 even be from a social worker or someone from a  
7 different team.

8 MEMBER SANDERS: I'm including  
9 everybody who is taking care of the patient while  
10 the patient's in the ICU.

11 CHAIR MORRISON: I'm seeing a lot of  
12 puzzled looks around the table. Neil, let me  
13 articulate something and tell me if I've got  
14 right or wrong. To get into the denominator, you  
15 have had to have been admitted into an, be a  
16 vulnerable elder by the ACO definition and be  
17 admitted into the Intensive Care Unit. For the  
18 numerator, therefore, it is the number of  
19 patients who, after admission to the hospital on  
20 this admission, had their advance directive or  
21 proxy designation documented in the medical  
22 record or a documentation of their care

1 preferences and you had up until 48 hours after  
2 ICU admission to see that documentation. Is that  
3 how I'm interpreting this correctly?

4 MR. WENGER: That is accurate except it  
5 had to be a preference documentation.

6 CHAIR MORRISON: I'm sorry, preference  
7 documentation.

8 MR. WENGER: Yes.

9 CHAIR MORRISON: Yes, sorry. And that  
10 -- so therefore, you got excluded from the  
11 numerator, you were a nay if that preference  
12 documentation occurred more than 48 hours after  
13 ICU admission or it did not exist at all during  
14 that index hospitalization. Is that correct?

15 MR. WENGER: Correct.

16 CHAIR MORRISON: Okay. I think -- let  
17 me see tent cards, I see a lot of hands.

18 Christine?

19 MEMBER RITCHIE: So, just to be clear,  
20 the documentation is not necessarily expected  
21 during the 48 hours during which they're in the  
22 ICU?

1 CHAIR MORRISON: That is correct. It  
2 has to have happened from the time of  
3 hospitalization up until the 48 hours after ICU  
4 admission. Anything after 48 hours doesn't  
5 count.

6 MEMBER RITCHIE: Right. So, I guess  
7 this may -- well, okay, fine.

8 CHAIR MORRISON: Let's see, I've got  
9 Amy and then, is that Tracy there, yes. Amy?

10 MEMBER BERMAN: So, if someone had an  
11 advance directive prior to the hospitalization  
12 and if, given the fact that 75 percent of people  
13 are unable to make some or all decisions at the  
14 end of life, they're admitted to the ICU unable  
15 to have their preferences obtained, are you  
16 saying that the clinician needs to document what  
17 already exists within the clinical record again?  
18 Is that -- and if that is the case, I'm just  
19 wondering how people feel about an advance  
20 directive on file, no ability to reach the  
21 family, no ability to have that meaningful  
22 conversation, and creating a set of meaningless

1 documentation. And I'm all for this in concept,  
2 but that's what I'm wondering, is that what you  
3 mean and is that what we're saying?

4 MR. WENGER: So, let me make sure that  
5 I understand what you're asking. So, there --  
6 let me first point out that most advance  
7 directives have little or no usable preference  
8 information in them. Then, luckily, that's  
9 becoming less and less common, less and less  
10 true, but it's still true today. So, there's a  
11 surrogate specified and maybe there's a box  
12 checked, but little other preference information  
13 would one find. But it's true that if an advance  
14 directive exists in the record, and there's no  
15 reference to that advance directive during the  
16 admission or a specification that we have only an  
17 advance directive here, no family is available  
18 and the patient can't talk to us, which would  
19 confer credit for this indicator, then the person  
20 would fail, correct.

21 CHAIR MORRISON: And I just want to  
22 remind folks, because we're getting a little

1 tangential, that we're still on reliability here.  
2 So, I'd like to sort of bring the discussion back  
3 to reliability.

4 MEMBER SANDERS: So, if I can follow up  
5 that lead, the measure is specified for paper  
6 charts. I mean, I think, as we discussed many  
7 times, what is abstractable from the paper chart  
8 is significantly also abstractable from an EMR.  
9 This measure is probably not conducive to  
10 reporting merely via structured data elements.  
11 And it's also to be reported at the facility  
12 level, so we can discuss whether that is the most  
13 appropriate level or not.

14 There was no updated reliability  
15 testing performed on this measure. From 2012,  
16 there was data from both ACO and ASSIST that  
17 showed kappas in the high eighties, 0.87 from the  
18 former and I believe 0.86 from the latter. The  
19 ASSIST study was limited to cancer patients, this  
20 measure is not. And both studies were internal  
21 studies from RAND, there wasn't really, to the  
22 best of my knowledge, any independent data



1 presented. And those are my comments on  
2 reliability.

3 CHAIR MORRISON: Open for discussion.  
4 Arif?

5 MEMBER KAMAL: Just real briefly, and  
6 file this under not allowing perfection to be the  
7 enemy of the good. But alignment with ACO and  
8 vulnerable elders makes sense for this specific  
9 measure, but as we think about moving forward and  
10 making a note, I mean, there's -- a patient with  
11 bad COPD with their second time in the ICU would  
12 not be in this denominator, right? So, patients  
13 with acute respiratory failure on ventilators,  
14 unless they have cancer or fall within the VES2,  
15 would not. So we'd be missing a lot of really  
16 important populations by this denominator. I  
17 think we should just note that, I don't think it  
18 makes this a bad measure, I think it makes this  
19 Measure a little bit more narrow than we  
20 eventually want it to be.

21 CHAIR MORRISON: Other comments on  
22 reliability? Yes, Linda? Mic?

1           MEMBER SCHWIMMER: I mean, just on its  
2 face though, there does seem to be an issue with  
3 reliability, because I don't know who's deciding  
4 whether the POLST form or the advance directive  
5 has enough information to be something that could  
6 be clinically followed. And unless that's  
7 specifically defined, I'm unsure if we really are  
8 getting at reliability.

9           CHAIR MORRISON: Other comments?  
10 Thoughts? Jean-Luc?

11           MR. TILLY: This is again a little bit  
12 of a different one, since reliability testing was  
13 conducted with just data elements. Your options  
14 are 1 for Moderate, 2 for Low, and 3 for  
15 Insufficient. So the results are 13 voting  
16 Moderate, eight voting Low, and three voting  
17 Insufficient. So the measure does not pass  
18 reliability.

19           CHAIR MORRISON: Sorry, guys, we're  
20 just checking on the process.

21           MS. JOHNSON: This would be in the gray  
22 zone. So what that means is, consensus not

1 reached, but we will continue.

2 CHAIR MORRISON: Amy, Validity?

3 MEMBER SANDERS: So for Validity, as a  
4 maintenance Measure, the question is has any  
5 updated information been presented? And the  
6 answer there is yes, but no. I do think that  
7 Validity needs to be revoted on. The -- sorry.  
8 From the previous data, the recommendation for --  
9 there was a, I think, a systematic review and the  
10 testing for validity at the data element level  
11 was, according to my notes, weak or absent. Hang  
12 on, let me look at my other notes so that I make  
13 more sense.

14 So, the ASSIST study included comments  
15 from three expert panels. The discussion  
16 regarding this Measure was not specific to this  
17 Measure. Advance care planning was kind of  
18 loosely lumped in with some other Measures  
19 related in sort of related areas. At least that  
20 was my reading of the study that was added to the  
21 shared site earlier this week. And the study was  
22 not conducted on ICU patients. So I found that

1 the data submitted in support of Validity was not  
2 as specific as I would have liked for the  
3 Measure. The Developers cited originally studies  
4 from 2001, 2005, and I think 2011, so much of  
5 that data is getting a little antiquated. And  
6 I'll stop there.

7 CHAIR MORRISON: Open for discussion.  
8 So, Amy, the NQF Staff had rated this as  
9 Insufficient, did your work group have strong  
10 feelings to change that in your discussions? Or  
11 I'll ask the other members of the group.

12 MEMBER SANDERS: Not to the best of my  
13 recollection.

14 CHAIR MORRISON: Okay. Jean-Luc?

15 MR. WENGER: This is Neil. Can I ask  
16 a question?

17 CHAIR MORRISON: Of course.

18 MR. WENGER: So, the sort of face  
19 validity that exists for this Measure is  
20 identical to the other Measures that we have  
21 discussed before. In other words, structured  
22 panel consideration. Actually, two separate

1 panels, ASSIST and ACO. And then a subsequent  
2 clinical panel review of the measures. So, I  
3 guess I wouldn't understand why the face validity  
4 considerations for this measure would be any  
5 different. This Measure also plays a role in the  
6 overall process outcome link evaluation that ACO  
7 did, because there were substantial numbers of  
8 these patients within that cohort. And of  
9 course, that cohort showed that process and  
10 outcome were linked for both mortality and  
11 function.

12 CHAIR MORRISON: That's helpful, Neil.  
13 I think we're just checking some paperwork here  
14 because it wasn't clear that the face validity  
15 and expert panel review details were provided to  
16 us. So I'm just checking with NQF to find out if  
17 they have them. And Karen is saying --

18 MS. JOHNSON: I'm actually going to run  
19 it by Neil and make sure we understand, but you  
20 provided a document talking about four different  
21 -- sorry, the ACO 3, the ASSIST panels with the  
22 steps, is that the same panels that looked at

1       this Measure, Neil?

2                   MR. WENGER: Correct.

3                   MS. JOHNSON: Okay. Then we do have  
4       the face validity results.

5                   CHAIR MORRISON: So, I will rephrase  
6       that. So we do have the data of the face  
7       validity that we applied to all of the other ACO  
8       Measures that we've been looking at. So that  
9       means that our -- sorry, Amy?

10                  MEMBER SANDERS: I would just -- yes.  
11       I would just add though that this Measure is a  
12       little bit different. The Measure does not apply  
13       to cancer patients only, it's much broader than  
14       that. And even though it's, I guess, it's  
15       subsumed under the rubric of the ASSIST panel,  
16       but to my reading of that document, it wasn't  
17       very specifically discussed. So I think that  
18       there are potentially some issues regarding face  
19       validity with specific reference to this Measure  
20       that may not have applied to some of the earlier  
21       Measures that we discussed.

22                  CHAIR MORRISON: Fair enough. So I

1 would say, we should go to a vote and then vote  
2 your conscience.

3 MR. TILLY: Okay. So, again, just  
4 three options here since we only did face  
5 validity testing. So 1 for Moderate, 2 for Low,  
6 and 3 for Insufficient. Okay. So the results  
7 for Validity are eight voting Moderate, 11 voting  
8 Low, and five voting Insufficient. Which is, I  
9 believe, it does not pass.

10 CHAIR MORRISON: So, at this point, we  
11 stop, because it doesn't pass. So, what I would  
12 say is, let's take a 15 minute break, we'll come  
13 back after five after four. We will work as hard  
14 as we can up until our stop time and then, I  
15 think we will defer to the morning. Yes? Or are  
16 we going to the end, Karen? You tell me.

17 MS. JOHNSON: We will talk to the folks  
18 from ASCO and see what they have to say.

19 CHAIR MORRISON: And we will -- but  
20 let's, everybody looks really tired, this has  
21 been a great discussion, so thank you for that,  
22 but let's break. Come back promptly at five

1 after, or be seated at five after.

2 (Whereupon, the above-entitled matter  
3 went off the record at 3:49 p.m. and resumed at  
4 4:05 p.m.)

5 CHAIR MORRISON: All right, folks. We  
6 are back, and we are into the home stretch.

7 We have modified the agenda just a  
8 little bit. We are going to go back and do the  
9 two UNC PEACE measures, which will get us  
10 probably till about 5 o'clock, maybe a little bit  
11 earlier, and then tomorrow morning, we're going  
12 to start bright and fresh and early and go  
13 through the ASCO measures we didn't get through  
14 tonight.

15 There is -- we will still do -- we  
16 will still do just fine. We are cautiously  
17 optimistic that we will not need two hours for  
18 the CAHPS measures tomorrow, which is what we  
19 allocated. And also, I suspect after you guys go  
20 home and sleep -- sleep a little bit, you will be  
21 -- have sort of gotten into the groove of what  
22 this is like, so I think we will be -- we are



1 continuing to move quickly. We are continuing to  
2 gel, but tomorrow morning, we will have really  
3 gelled.

4 So with that being said, let us move  
5 on to 1641, Hospice and Palliative Care Treatment  
6 Preferences. Dr. Hanson is with us again.  
7 Laura?

8 MS. HANSON: I am back, and I will say  
9 that I was very interested in the discussion of  
10 the previous measure because I think it  
11 illustrates some of the challenges in specifying  
12 a measure for this particularly, I think,  
13 compelling area of palliative and -- palliative  
14 care and hospice.

15 So the 1641 --

16 CHAIR MORRISON: I am sorry Laura, I  
17 need interrupt just for -- just for everybody  
18 else, Christine is recused from this, so she  
19 can't play with us in the sandbox for this one.  
20 Sorry, Laura, go ahead.

21 MS. HANSON: The -- I'll miss your  
22 wisdom.

1           The -- the treatment preferences  
2       measure is also from the PEACE measure set and  
3       was developed for parallel use in palliative care  
4       and hospice populations. The measure is designed  
5       to capture medical record documentation of  
6       communication of treatment preferences for  
7       individuals during the initial assessment phase  
8       of palliative care for hospice enrollment, and I  
9       think I will leave it there unless people have  
10      additional questions, and I'll be happy to answer  
11      them.

12           CHAIR MORRISON: Fantastic. So I have  
13      as the discussants -- hang on just a second, guys  
14      -- yes, I've got Linda and George. I think,  
15      Linda, I have you as the lead. Is that right?

16           MEMBER SCHWIMMER: Right. I am going  
17      to --

18           CHAIR MORRISON: Not George, yes.  
19      Linda --

20           MEMBER SCHWIMMER: Yes.

21           CHAIR MORRISON: -- go ahead.

22           MEMBER SCHWIMMER: I'm going to take

1 the first one and go --

2 CHAIR MORRISON: Yes, that is perfect.

3 So you want to talk to us about evidence?

4 MEMBER SCHWIMMER: Yes. So the NQF  
5 staff rated this as moderate, and the committee  
6 agreed. There was a systematic review, and there  
7 was -- although the -- the developers didn't  
8 reference -- oh, this is a maintenance and this  
9 is a process measure.

10 Although the developers didn't mention  
11 new evidence, there were two pretty recent  
12 studies and a lot of publications out there about  
13 the importance of -- of documenting your wishes,  
14 and there was a lot of -- there was a lot of  
15 evidence as well that was supplied by the -- by  
16 the developers, so that was rated by moderate,  
17 and the committee agreed on that, and happy to  
18 answer any questions, or we can keep moving.

19 CHAIR MORRISON: If there's no  
20 objection, given that this is in maintenance, up  
21 for maintenance, we can skip forward to gap  
22 without a vote.

1 (No response.)

2 CHAIR MORRISON: Onwards.

3 MEMBER SCHWIMMER: Okay. As far as  
4 gap goes, this measure on its face looks like  
5 it's tapped out, and that's probably because of  
6 the -- the definition, so with the -- I am  
7 looking right here for my highlighted numerator  
8 and denominator, here we go.

9 So -- so the -- the numerator in  
10 hospice situations, in hospice settings, is  
11 patients whose medical record includes  
12 documentation of life-sustaining preferences, and  
13 the denominator is patients enrolled in hospice.  
14 So I mean obviously the group that you're looking  
15 at already had to have a conversation to be  
16 enrolled in hospice, and now you're -- you're  
17 looking at how many people have documented their  
18 preferences.

19 So the measure for hospice looks  
20 relatively tapped out, but the palliative care,  
21 this is one of those ones like we talked about  
22 this morning where we're still waiting on

1 information, and so since that information is  
2 coming soon, it is not clear, you know, whether  
3 there is room for improvement there or not at  
4 this point.

5 There were some -- some disparities by  
6 -- there was some data collected by race, and  
7 there were some disparities, so there could be  
8 some improvement because there were differences.

9 CHAIR MORRISON: George, anything to  
10 add to that?

11 (No response.)

12 CHAIR MORRISON: So again, just  
13 because I know people are tired, in the morning  
14 we faced this with many of the UNC measures that,  
15 on the palliative care data, were not here yet,  
16 but they're coming soon, and my recollection was  
17 that we accepted that in the morning.

18 MS. HANSON: And I guess I -- I would  
19 just -- I do endorse what Sean just said, and I  
20 would just add, although I recognize that it's  
21 older data in terms of the gap, the data from the  
22 prior submission with the palliative care

1 population showed that with the serious illness  
2 population in the hospital, documentation of  
3 preferences 59 percent of the time, that  
4 increased to 91 percent after involvement of  
5 specialty palliative care, so. And I will just  
6 give that to you as part of your consideration.

7 CHAIR MORRISON: Okay. Questions,  
8 comments from the committee? Jean-Luc?

9 MR. TILLY: Okay, to vote for  
10 performance gap on 1641, select high -- or select  
11 1 for high, select 2 for moderate, 3 for low, and  
12 4 for insufficient.

13 Okay. And the votes are two voting  
14 high, 18 voting moderate, and two voting low, and  
15 zero voting insufficient, so the measure passes  
16 performance gap.

17 MEMBER SCHWIMMER: Okay --

18 CHAIR MORRISON: Linda, onwards and  
19 upwards?

20 MEMBER SCHWIMMER: So on reliability,  
21 the NQF team gave it a moderate. The only -- the  
22 only issue that really -- the only issue that

1 really came up in the conversation was there was  
2 some question about the definition of how you  
3 were actually capturing patients' wishes, and --  
4 and we discussed the fact that it's -- it's  
5 pretty specifically laid out in the HIS manual,  
6 which this is used as part of the hospice quality  
7 of scoring, and in that manual, it lays out  
8 specifically what is required in a very guide-  
9 like sort of way.

10 And so that's what was -- that's what  
11 was used, and there's pretty -- pretty large  
12 sample size, and so a good sense of reliability.

13 CHAIR MORRISON: George?

14 (No response.)

15 CHAIR MORRISON: Committee?

16 (No response.)

17 CHAIR MORRISON: Jean-Luc.

18 MR. TILLY: So to vote for  
19 reliability, select 1 for high, 2 for moderate, 3  
20 for low, and 4 for insufficient.

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

1       insufficient, so the measure passes reliability.

2               MEMBER SCHWIMMER:  Again, on validity,  
3       this was also graded as -- as moderate, and the  
4       committee agreed.  Large sample size, there was  
5       correlation between the other measures and how  
6       this one stacked up, the other measures in the  
7       set of six that are used for the hospice quality.  
8       There were no questions or concerns on validity.

9               CHAIR MORRISON:  George?

10              (No response.)

11              CHAIR MORRISON:  Committee?

12              (No response.)

13              CHAIR MORRISON:  Jean-Luc.

14              MR. TILLY:  So to vote for validity,  
15       select 1 for high, 2 for moderate, 3 for low, and  
16       4 for insufficient.

17              MEMBER SCHWIMMER:  So with the  
18       exclusions --

19              CHAIR MORRISON:  Hang on just a --

20              MEMBER SCHWIMMER:  Oh --

21              CHAIR MORRISON:  -- second --

22              MEMBER SCHWIMMER:  -- sorry --



1 CHAIR MORRISON: -- Linda, sorry, I  
2 think we're still collecting votes.

3 MEMBER SCHWIMMER: Oh, sorry.

4 MR. TILLY: Okay. The votes are zero  
5 for high, 22 for moderate, zero for low, zero for  
6 insufficient. The measure passes validity.

7 CHAIR MORRISON: Feasibility.

8 MEMBER SCHWIMMER: Feasibility. So  
9 feasibility, this is currently routinely  
10 collected. It is used by CMS as part of their  
11 quality measure set, and it's -- according to the  
12 developers, it's extracted from the electronic --  
13 the EHR.

14 CHAIR MORRISON: Team, Karen reminds  
15 me that we can carry feasibility and usability  
16 forward if we would like, given the other UNC  
17 measures that we've agreed to. Any objections?

18 (No response.)

19 CHAIR MORRISON: Then we will move  
20 those forward.

21 And I think that brings us to the  
22 overall vote, right? All right. Yes or no, red

1 or blue states.

2 MR. TILLY: The results are 22 voting  
3 yes, zero voting no, so the measure is  
4 recommended for endorsement.

5 CHAIR MORRISON: I am Canadian, so I  
6 don't know what red or blue means, so we will  
7 move on.

8 (Laughter.)

9 CHAIR MORRISON: We're going to move  
10 to 1647, which is Beliefs and Values  
11 Documentation. Laura?

12 MS. HANSON: So the last of the PEACE  
13 measures that are before you. I will add the  
14 caveat that this was -- this was originally a  
15 PEACE measure. There was additional work done on  
16 it by a different organization that became the  
17 measure steward, and then about two months before  
18 this meeting, it was passed back to UNC as the  
19 measure steward, so I am going to do the very  
20 best that I can with this information.

21 But basically, this is a quality  
22 measure to capture the challenge to

1 hospice/palliative care providers that they  
2 address individuals' spiritual needs and concerns  
3 during the initial assessment of their needs in  
4 various palliative care domains. I will say that  
5 one issue that came up in the NQF review that  
6 I'll just clarify at this point is that there was  
7 a question about whether the measure  
8 specifications were modified.

9 My answer to that question would be  
10 no. For the hospice item set, the data-capture  
11 period is five days, which is the data capture  
12 period that was set by CMS for the initial  
13 comprehensive assessment, and so to us, that's  
14 not a change in the specifications of the  
15 measure, but it is matching the initial  
16 assessment period to the period that CMS  
17 specified.

18 CHAIR MORRISON: Terrific, and I think  
19 George is taking the lead -- Alice, I must  
20 apologize to you on the phone. You're on the  
21 second line of my cheat sheet, and I didn't see  
22 you as a discussant, so I am assuming that you

1 will jump forward if you have something to add.

2 Is that all right?

3 MEMBER LIND: Yes, go ahead.

4 CHAIR MORRISON: Great. George?

5 Evidence.

6 MEMBER HANDZO: So this is a direct  
7 measure, the percentage of hospice patients over  
8 18 years old who have documentation in the  
9 clinical record of a discussion of  
10 spiritual/religious concerns or documentation  
11 that the patient or caregiver did not want to  
12 discuss these concerns, and that takes place  
13 within five days of admission to hospice.

14 This is a process measure here for  
15 maintenance review. The -- and oh, let me -- I  
16 am sorry, I missed something, back for a second,  
17 I failed to say this morning, which I thought I  
18 probably should say now, is that part of the  
19 evidence for this is the NCP guidelines, and I  
20 did serve in the leadership on the -- not NCP,  
21 but the National Consensus Conference guidelines,  
22 which provided the text, a lot of text for Domain

1 -- what you now see in Domain 5, so I never  
2 worked on this measure, I never worked on NCP,  
3 but I do have some knowledge of this.

4 So there are several guidelines  
5 including NCP and NQF performance measures, but  
6 there -- it does lack a research literature  
7 including any systematic review or QC data, and  
8 then I am unaware of any systematic review or  
9 expert opinion on this.

10 The developers do report a new  
11 guideline. However, it does not appear that that  
12 changes the basic thrust of the guidelines  
13 already presented. The measure was originally  
14 approved as insufficient evidence with exception.  
15 Recommendation of staff is to continue that  
16 exception, and that seems reasonable and  
17 appropriate for a number of reasons, given that  
18 this is the only spiritual care measure currently  
19 approved.

20 There also are, in terms of the  
21 exception, there are -- I think one of the  
22 characteristics is that there -- it's not a

1       burden, and there are numerous studies that  
2       suggest that patients and family members want to  
3       discuss this and that they in fact contrary to --  
4       that not only don't they find it a burden, they  
5       find it a welcome discussion to have.

6               So given that, I would suggest the  
7       continuing of the no evidence with -- exception  
8       -- insufficient evidence with exception, that's  
9       what it is.

10              CHAIR MORRISON:  Alice, Linda,  
11       anything to add?

12              (No response.)

13              CHAIR MORRISON:  From the committee?  
14       Arif, is that a card or a finger or is that --

15              MEMBER KAMAL:  It's both.

16              CHAIR MORRISON:  Both.

17              MEMBER KAMAL:  For emphasis.

18              CHAIR MORRISON:  Yes, go ahead.

19              MEMBER KAMAL:  Actually just a real  
20       quick question of Laura: so I noticed the NQF --  
21       the press release from 2012 and the Measurement  
22       Matters gives this credit of this measure to

1 DATA, but can you just clarify the relationship  
2 between DATA and UNC and the PEACE Project and  
3 all that, because --

4 MS. HANSON: I have no relationship  
5 with DATA, except that DATA was the organization  
6 that, after the PEACE Project, for a variety of  
7 important reasons, they contractually picked up  
8 the responsibility to be the measure steward and  
9 to do additional testing on this measure, and  
10 they maintained that status until about two  
11 months prior to this meeting, where they asked to  
12 pass this measure-steward role back to UNC.

13 CHAIR MORRISON: Other comments,  
14 thoughts?

15 (No response.)

16 CHAIR MORRISON: Guess we'll go to a  
17 vote.

18 MR. TILLY: So we're voting on  
19 evidence for 1647. Select 1 for high, 2 for  
20 moderate, 3 for low, and 4 for insufficient.

21 All right. So the results are one  
22 voting high, eight voting moderate, and 14 voting

1       insufficient.

2                   MS. JOHNSON:   So my calculator tells  
3       me that insufficient is 60.9 percent.   That is  
4       over our 60 limit, so that actually leads us to  
5       the question of does this go forward with the  
6       exception?

7                   CHAIR MORRISON:   So on the basis of  
8       0.9 percent, we'll go to the next vote.

9                   MS. JOHNSON:   Actually, can you hold  
10      on just a second?   Let me redo that math.   What  
11      was the -- yes, I think I might have used 24.  
12      Let's make sure.

13                  MS. WILSON:   I got 61 percent with 23  
14      --

15                  MS. JOHNSON:   I was going to say --

16                  PARTICIPANT:   -- yes.

17                  MS. JOHNSON:   -- it's better than  
18      that, so --

19                  CHAIR MORRISON:   So with --

20                  MS. JOHNSON:   -- yes.

21                  CHAIR MORRISON:   -- a whole 0.1 --

22                  MS. JOHNSON:   Yes.



1 CHAIR MORRISON: -- percent more --

2 MS. JOHNSON: Apologies, I was using  
3 the wrong denominator, Christine, I forgot.

4 CHAIR MORRISON: Let's go to the next  
5 vote.

6 MR. TILLY: Very good. To vote on  
7 whether or not an exception will be permitted to  
8 evidence, select 1 for -- to pass it as  
9 insufficient evidence with exception and 2 for no  
10 exception.

11 So 22 voted insufficient evidence with  
12 exception, and one voted no exception, so the  
13 measure passes evidence with exception.

14 CHAIR MORRISON: Onwards to gaps.  
15 George?

16 MEMBER HANDZO: So the developer does  
17 provide data on the normally investigated groups  
18 for disparity analysis. There are significant  
19 differences reported statistically, and I think  
20 the question from the staff, I think rightly, is  
21 are those -- they're statistically significant.  
22 Are they clinically significant?

1           My -- my sense would be that given the  
2       sensitivity of this -- this data, and -- and what  
3       we're talking about, I am -- I am loath to  
4       dismiss this as clinically insignificant. You  
5       know, it just -- I think it deserves a little  
6       more work than to just say, well, it's -- it's  
7       statistically significant, but we're just going  
8       to make a judgment that it's clinically  
9       insignificant, and I think we need some more data  
10      in order to make that decision.

11           The -- so the next question is, you  
12      know, has this measure topped out? There -- the  
13      developers do show that about 20 percent of the  
14      population is significantly below the national  
15      mean, and we don't really know yet, I don't  
16      think, or I don't see the data for what that  
17      actually represents.

18           Are there some disparities hidden in  
19      there or whatever? We don't quite know. I mean,  
20      I can't figure out from this data, and maybe the  
21      developers can add wisdom to that, but I would  
22      argue that the -- that there are -- there are

1 performance gaps here that continue to need to be  
2 addressed.

3 CHAIR MORRISON: Linda, Alice?

4 (No response.)

5 CHAIR MORRISON: George, was there a  
6 question to Laura in there?

7 MEMBER HANDZO: No.

8 CHAIR MORRISON: Okay. Other  
9 thoughts, questions from the committee? Arif.

10 MEMBER KAMAL: So we've done a five-  
11 sided study through the PCRC, you know, looking  
12 at adherence to this measure specifically, and  
13 found that in acute care settings, so ICUs, ERs,  
14 it's only 17 percent, and in outpatient and home  
15 settings, it only gets as high as 47 percent.

16 So we have made this a major quality  
17 improvement project within our own group, and  
18 it's still with a lot of pushing have not seeing  
19 closure of that gap, so I think it's an important  
20 gap that's still open.

21 CHAIR MORRISON: I just need to ask  
22 Laura a quick question. I mean, my understanding

1 was the denominator here was just hospice. Is  
2 that right? Yes, okay --

3 MS. HANSON: That is correct. So this  
4 -- this is all hospice data, and that in part  
5 reflects the transition in the measure steward,  
6 but yes, everything presented here is hospice.

7 MEMBER HANDZO: Yes, I am sorry. The  
8 good news for the group here is that we're not  
9 having to deal with this hospice/palliative care  
10 thing in this measure.

11 CHAIR MORRISON: Other thoughts?

12 (No response.)

13 CHAIR MORRISON: Let's go to a vote.

14 Jean-Luc.

15 MR. TILLY: To vote on performance gap  
16 for 1647, select 1 for high, 2 for moderate, 3  
17 for low, and 4 for insufficient.

18 The results are zero voting for high,  
19 23 voting for moderate, zero voting for low, and  
20 zero voting for insufficient, and the measure  
21 passes performance gap.

22 CHAIR MORRISON: Onwards, George.

1                   MEMBER HANDZO: Reliability: so the  
2                   measure is specified for the facility level of  
3                   analysis, and, as we said, hospice in this case  
4                   only.

5                   The numerator and the denominator are,  
6                   to my view -- now I will say that I am now into  
7                   an area that I told people my last statistics  
8                   course was someplace in the 1980s, so I disclose  
9                   that this is not my strong suit.

10                  So -- but I think the -- the -- it  
11                  seems fairly well specified, and the testing  
12                  there was split-half analysis where the result  
13                  was 0.94, and a signal-to-noise ratio of 0.99, so  
14                  the reliability testing seems appropriate. The  
15                  sample size, as previously discussed, was large,  
16                  and the staff rated this reliability as high, and  
17                  I concur.

18                  CHAIR MORRISON: Linda, Alice,  
19                  anything to add?

20                  (No response.)

21                  CHAIR MORRISON: Anything from the  
22                  group?

1 (No response.)

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

5 The results are 12 for high, 11 for  
6 moderate, zero for low, and zero for  
7 insufficient, so the measure passes reliability.

8 MEMBER HANDZO: So the validity, this  
9 is where the caveat that Dr. Hanson described at  
10 the beginning kicks in in terms of the measure  
11 being passed back and forth and the staff noting  
12 correctly in the -- that this was marked as  
13 tested with a modified version, and so there was  
14 a question about how it was modified, and does  
15 that invalidate the specifications of the  
16 measure?

17 And I think I would agree with Dr.  
18 Hanson that it in fact does not. So that was the  
19 major question with validity.

20 Otherwise, the -- the testing is -- is  
21 adequate. The kappa score, there's a kappa score  
22 which falls into the category of substantial. I

1 think it's like 0.79 or something like that if I  
2 remember correctly. So high enough to be -- to  
3 be good.

4 The threats to validity, the -- the  
5 developers tested the persons under 18 years of  
6 age and found minimal impact on the result, and  
7 so that exclusion doesn't seem to be a threat to  
8 validity in this measure.

9 The measure does appear to be able to  
10 identify meaningful differences in performance,  
11 and because this is in HIS, the missing data as  
12 usual in this measure is minimal. There is no  
13 risk adjustment.

14 So the -- okay, I'm off into validity,  
15 so that's the validity -- the validity report.

16 CHAIR MORRISON: Linda, Alice?

17 (No response.)

18 CHAIR MORRISON: Committee?

19 I don't think you can -- oh, you're  
20 not? Never mind. You may weigh in. Please,  
21 Christine, speak to us.

22 MEMBER RITCHIE: I promised you I

1 wouldn't talk to you about this.

2           So I guess the question I had to Karen  
3 maybe is that this -- this, unless I am  
4 misreading it, this received an insufficient --  
5 this received an insufficient, and I was just  
6 wondering your thoughts about that.

7           MS. JOHNSON: Yes. It goes back to  
8 that modified question. Basically, what we  
9 require is that testing be with the measure as  
10 specified, so the testing, the correlation  
11 analysis that they used, had that modified on it,  
12 so they're testing the modified version, and so  
13 we didn't know how different the modified was  
14 from this one.

15           So that was why we had that question.  
16 If -- if we're happy that the modified isn't  
17 really that different, it's a matter of timing,  
18 then we can take the testing as fine.

19           MEMBER HANDZO: There was just a -- it  
20 just appeared kind of in the validity testing,  
21 there was this thing, the measure and it said in  
22 brackets modified and without specifying what



1       that was, and so we didn't know.

2                   CHAIR MORRISON:  Other thoughts,  
3       questions?

4                   (No response.)

5                   CHAIR MORRISON:  Should we vote on  
6       validity, Jean-Luc?

7                   MEMBER MOSS:  So I am confused.

8                   CHAIR MORRISON:  Woody?

9                   MEMBER MOSS:  You've lost me.  So how  
10      can we not know how they modified the question?  
11      I mean, we're scientists, right?  I mean --

12                   MEMBER HANDZO:  We do know now.  She  
13      just -- it wasn't in the report.

14                   MEMBER MOSS:  Okay.

15                   MS. HANSON:  And I am happy -- I am  
16      happy to describe it again.

17                   So basically, the measure  
18      specification is that the spiritual -- the  
19      assessment of spiritual needs and concerns would  
20      happen during the initial assessment by the  
21      hospice or palliative care provider.  That was  
22      how the measure was specified.

1 CMS then moved in and said there's a  
2 five-day window for the initial assessment, which  
3 is then basically what's used in the HIS for its  
4 implementation. The measure specification itself  
5 doesn't change. This is kind of back to the  
6 beginning, the morning, in that this is really  
7 implementation matching CMS's definition of the  
8 initial assessment.

9 MR. TILLY: Okay, so voting is now  
10 open on validity. Select 1 for high, 2 for  
11 moderate, 3 for low, and 4 for insufficient.

12 The results are zero voting high, 21  
13 voting moderate, zero voting low, and two voting  
14 insufficient. The measure passes validity.

15 CHAIR MORRISON: And George, wrap it  
16 up with feasibility and usability.

17 MEMBER HANDZO: Feasibility: all the  
18 data elements are routinely generated and  
19 available in electronic form. While this measure  
20 would seem to be -- I'm going to talk a little  
21 bit -- I will say something about that in --  
22 about obvious care delivery potential, the

1 developers don't report on that, nor are they  
2 really required to.

3 So it is -- it would seem essential,  
4 and there is a rationale for having a continuous  
5 measure which I think is legitimate.

6 CHAIR MORRISON: And I am told by  
7 Karen that again, we can carry this over from  
8 this morning if there are no objections. It  
9 doesn't need a vote.

10 MS. JOHNSON: And let's make sure that  
11 I'm not mistaken. This is one of the HIS  
12 measures. It's collected in the same way --

13 MEMBER HANDZO: Yes.

14 MS. JOHNSON: -- used in the same way  
15 --

16 MEMBER HANDZO: Yes, that is accurate.

17 MS. JOHNSON: Okay.

18 CHAIR MORRISON: So we can move on to  
19 usability. George?

20 MEMBER HANDZO: Yes. There do not  
21 seem to be any related or competing measures  
22 here. The -- the developers do report some data

1       which suggests that more patients who had a  
2       documented discussion had improved their  
3       spiritual distress scores. They do report that  
4       they cannot yet have sufficient longitudinal data  
5       to report on improvement of use. They also  
6       report no unexpected findings and no unintended  
7       consequences.

8               I would simply add here that this is  
9       the only spiritual care measure, and it is I  
10      think critical to what Dr. Hanson started out  
11      with about this being kind of in a -- in a field  
12      by itself, that it is out of this data that we're  
13      going to be able to start to generate data about  
14      who wants to have the discussion, what do they  
15      discuss, what are the issues they raise, and  
16      that's going to drive our interventions, so it's  
17      off this data that we're going to start to be  
18      able to get a handle finally on this whole area  
19      of care which we do not have presently evidence  
20      for.

21               CHAIR MORRISON: Alice, Linda,  
22      anything to add?

1 (No response.)

2 CHAIR MORRISON: Committee?

3 (No response.)

4 CHAIR MORRISON: And again, we can  
5 carry forward this morning for the -- unless I  
6 hear any objections.

7 Hearing none, we will carry that  
8 forward, and we'll go to the overall vote on  
9 endorsement.

10 MR. TILLY: So to answer the question  
11 does the measure meet NQF criteria for  
12 endorsement, select 1 to vote yes and select 2 to  
13 vote no.

14 The results are 22 voting yes, one  
15 voting no. The measure is recommended for  
16 endorsement.

17 CHAIR MORRISON: Thank you, guys.  
18 That was perhaps the smoothest and least  
19 contentious discussion on spirituality in  
20 palliative care I have ever experienced at any  
21 time.

22 So with that, I think we are done with

1 the measures for today, so I'm going to turn it  
2 over to Karen. We're going to talk -- do the  
3 related and competing discussion, and then open  
4 it up at the end for public comment, and then  
5 we'll talk a little bit about tomorrow.

6 MS. JOHNSON: Okay. Jean-Luc, if you  
7 will just pull the very last slide in our deck.  
8 I think this is actually going to go very  
9 quickly, but then again, I was told that I jinxed  
10 us this morning by saying that we would get -- so  
11 I won't say that, I am sorry, just forget I said  
12 that.

13 These are the measures that I have  
14 pulled together for us to talk about, not as  
15 competing measures, but just related measures  
16 that are doing similar things, and I wanted to  
17 get your feedback on these.

18 However, Measure 1626, the care  
19 preferences -- no, I'm not sure, which one did we  
20 just do? We just did 1641. So 1626 is the one  
21 that we did not put forward as suitable for  
22 endorsement.

1           So just pretend that first column  
2 isn't there. Because we did not find it suitable  
3 for endorsement, we will not be having this  
4 discussion about related and competing.

5           So again, I am not asking you to make  
6 any decisions. I really wanted to just let you  
7 see a little bit of the difference between the  
8 treatment preferences measures that we talked  
9 about a couple minutes ago and another measure  
10 that we have in the portfolio. It's advance care  
11 plan.

12           The advance care plan measure is -- it  
13 actually hits pretty much all settings, and I  
14 didn't put all the lists there. There might be  
15 one or two that it's not there, but it's really  
16 specified for a lot of different places. The  
17 same level of analysis,  
18 clinician/individual/group practice.

19           The patient population is much  
20 broader. It is looking at all patients 65 and  
21 older. But the numerator is -- is quite  
22 different, so it's a documented advance care plan

1 or surrogate or documentation of discussion.

2 So I think my question to you is as  
3 overseer of the portfolio, how -- can you explain  
4 how the -- the two measures are different, the  
5 treatment preferences versus advance care plan,  
6 and would you have any suggestions about, you  
7 know, is this something that one could combine  
8 and make one measure that does everything? And  
9 possibly not. So I am just wanting your feedback  
10 on -- on this.

11 CHAIR MORRISON: And the cards go up.  
12 Okay.

13 (Laughter.)

14 CHAIR MORRISON: I've got Michelle,  
15 I've got Woody, I've got Karl, I've got Amy.  
16 Michelle -- and Paul. Michelle, start us off.

17 MEMBER CAUGHEY: Thank you.

18 We are in the process of trying to  
19 implement both of these things for four million  
20 people, and they are very different, so that we  
21 would encourage everyone to have an advance care  
22 plan and to designate a surrogate, and that's



1 very different but related to patients who then  
2 subsequently or at certain times of life or, if  
3 possible, related to their age, but not quite as  
4 necessary, and you have a setting definitely in  
5 the hospice and hospital where you have then  
6 documentation of life-sustaining treatment.

7 So they are related, but I think we  
8 need to see that this process is a stepped  
9 process as we move patients along in their  
10 journey of all of us through life, and that the  
11 very first thing is to designate the surrogate,  
12 and then when we're comfortable and we -- and we  
13 should move on to that second step or third step.

14 CHAIR MORRISON: Woody, you were  
15 almost as aggressive as Michelle with your card.

16 MEMBER MOSS: So -- and unfortunately,  
17 I disagree with Michelle. I think this is a  
18 stepped process, but it's a spectrum, it's a  
19 continuum, and in fact, I've been giving talks  
20 ever since Medicare and insurers started paying  
21 for advance care planning.

22 We start with the 18- or 19-year-old

1 who might want to designate who they would want  
2 to have as their decision-maker, but they also  
3 may have values that they would want to do a  
4 living will as well as a durable power of  
5 attorney for healthcare, and then as they develop  
6 a life-limiting illness, they may want to revisit  
7 things, but then if you wouldn't be surprised if  
8 they died in the next year, which is sort of  
9 further along in the spectrum, then you might  
10 want to then more specifically talk about what's  
11 in a POLST form and their life-sustaining  
12 treatment preferences.

13 But remember, if they've done a living  
14 will at the age of 21 saying I wouldn't want to  
15 be -- you know, have my dying prolonged if I'm  
16 dying or permanently unconscious, they're already  
17 stating some preferences with regard to life-  
18 sustaining treatment.

19 So I think these two can be lumped if  
20 we have a broader understanding of what advance  
21 care planning is, and I really would like to see  
22 us get rid of most of the restrictions. I mean,

1 it doesn't have to be -- you don't have to be  
2 over 65. You don't have to be in hospice or  
3 receiving specialty palliative care.

4 I think we believe it's part of good  
5 preventive healthcare to start having discussions  
6 with people. It's patient-centered care. It's  
7 just finding out what are their preferences, what  
8 are their life experiences, what did they see  
9 their mother go through, their father go through,  
10 their grandmother go through?

11 We start documenting, and as Michelle  
12 suggested, we come back and revisit as they  
13 proceed along their trajectory of their life, but  
14 I would love to see it as one broad,  
15 comprehensive thing that can be done on a  
16 repetitive basis over time.

17 CHAIR MORRISON: Karl?

18 MEMBER STEINBERG: So I partially  
19 agree with Woody. I think, you know, that last  
20 measure, why isn't it all patients over 18?  
21 That's what's really recommended. Everybody  
22 should, you know, document basic preferences and

1 designate a person. That's recommended for  
2 everyone.

3 But I also agree with Michelle. I  
4 think there are two very different things, and I  
5 -- I mean, everybody doesn't need to be deciding  
6 do they want a feeding tube, do they want CPR, do  
7 they want the ventilators, do they want, you  
8 know, transfusions or dialysis and that sort of  
9 thing. That's really for a select population.

10 So to me, I don't think these two  
11 could be -- could be lumped.

12 CHAIR MORRISON: Amy.

13 MEMBER BERMAN: I believe that these  
14 are two very different things as well, and while  
15 I do believe that they are on a continuum, I  
16 think that it is akin to the difference between  
17 palliative care and hospice. You can have  
18 palliative care within hospice, but palliative  
19 care is bigger than hospice.

20 And here, what we're talking about in  
21 terms of treatment preferences, this happens on  
22 diagnosis and is not necessarily related to end-

1 of-life care. This is a broader spectrum of, you  
2 know, do we understand what's important to you?  
3 And the buckets are independence, function, pain,  
4 length of life, and they're going to give it to  
5 you in their real words, but that is what the  
6 data would suggest. You know, those are kind of  
7 the buckets of treatment preference.

8 Advance care planning really is much  
9 more specific about end-of-life care and leads to  
10 advance directives, so these really are two  
11 different things. I will give you an example  
12 from myself. I have treatment preferences that  
13 have nothing to do with my end-of-life care that  
14 have led to my having very good care, and  
15 palliative care is a backbone of that. But my  
16 advance directives, I have a healthcare proxy,  
17 and my family is well aware of what my wishes are  
18 at the end of life, as are my clinical team. So  
19 very different things.

20 CHAIR MORRISON: Paul, are you up or  
21 are you down?

22 MEMBER TATUM: No, I have very little

1 because everything I wanted to say has been said,  
2 with the exception I agree with the differences  
3 between advance care planning and treatment  
4 preferences. I think as one gets closer to the  
5 hospice/hospital/end of life, you know, upstream  
6 treatment preferences shift, but I wanted to  
7 speak strongly in favor of 326. One of the  
8 things we've been missing is some of the primary  
9 care component, and the real strength of that is  
10 role of the primary care on that measure.

11 And the -- you know, the danger of  
12 relying too much on the 1641 is the importance of  
13 the primary care upstream, and the 326 takes it a  
14 little more strongly, but I think there is a  
15 difference, and I think as you get close to that  
16 shifting preferences that can happen, it is  
17 discrete where the 1641 has value.

18 CHAIR MORRISON: Deborah.

19 CHAIR WALDROP: Okay, so my two  
20 thoughts are -- my two cents and my two thoughts  
21 are first of all that people die in years, they  
22 die in months, they die in weeks, they die in

1 hours, they die in days, they die in minutes, and  
2 when the focal length changes so do people's  
3 wishes often, and I think it is really important  
4 -- I feel strongly that these are very -- two  
5 very separate processes, as Michelle has said,  
6 and that to blur them would take away how the  
7 focal length really shifts people's preferences.

8 And the second thought that I want to  
9 share is work that Andrew Billings and Rachelle  
10 Bernacki recently published on the Goldilocks  
11 phenomenon, that you can have advance care  
12 planning that is done well too far in advance,  
13 like, you know, it's too hot; they can -- you can  
14 have it too cold when it's very close to the very  
15 end; or you can have it just right, like  
16 Goldilocks.

17 And for me, it's the just right, the  
18 tipping point, that we're looking for. And so I  
19 think it's very sensitive, and we need to be able  
20 to see them as very separate processes.

21 CHAIR MORRISON: Cindi?

22 MEMBER PURSLEY: I just wanted to

1 clarify that for treatment preferences from a  
2 hospice perspective, do you want to have  
3 antibiotics? Do you want hydration? Those are  
4 the types of things. It's not -- they're very  
5 separate from advance directives and CPR and  
6 proxies and those kinds of things. These are  
7 truly about the -- the treatments for comfort in  
8 the last days, weeks, or months of life. And so  
9 it's a -- to me, they are completely and totally  
10 separate.

11 CHAIR MORRISON: Karl, you get the  
12 last word.

13 MEMBER STEINBERG: Woo-hoo.

14 CHAIR MORRISON: That was a good last  
15 word.

16 So Karen, I think there was some  
17 strong opinion. I hope you got it. Anybody else  
18 want to weigh in on this one?

19 (No response.)

20 CHAIR MORRISON: So if not, then we  
21 now turn to public comments, and first from the  
22 phone lines, so if I could ask the operator to



1 open up the phone lines for public comment?

2 THE OPERATOR: Okay. At this time, if  
3 you would like to make a comment, please press  
4 star, then the number 1.

5 There are no public comments at this  
6 time.

7 CHAIR MORRISON: Thank you. And then  
8 I look to those folks in the room, and if you  
9 could come up to the mic, that would be terrific.

10 MS. SINCLAIR: Hello, my name is  
11 Stacie Sinclair, and on behalf of the Center to  
12 Advance Palliative Care and our partner  
13 organizations within the National Coalition for  
14 Hospice and Palliative Care, we wanted to thank  
15 the standing committee for the excellent work  
16 that they have done thus far.

17 Many of the points that you  
18 deliberated are well taken and speak to the gaps  
19 that we have in the field. We do want to  
20 reiterate, however, that there are very few NQF-  
21 endorsed palliative care and hospice measures.  
22 This not only has implications for quality

1 improvement but for the thousands of palliative  
2 care providers in whether they can be adequately  
3 measured under the burgeoning pay-for-performance  
4 programs.

5 In order to move the field forward in  
6 quality measurement and get to a place where  
7 next-level measures can be developed and  
8 considered, it is critical to maintain the  
9 foundation that our measure developers have spent  
10 many years building. Therefore, we just wanted  
11 to voice our support for protecting the  
12 endorsement of all the quality measures that we  
13 currently have, including 1639, 0209, and 1626.  
14 Thank you very much.

15 CHAIR MORRISON: Thank you, Stacie.  
16 Others?

17 (No response.)

18 CHAIR MORRISON: So just before I turn  
19 things back to Rachel, I wanted to express both  
20 Deborah's and my thanks for a very productive  
21 and, I know, long day. I will tell you my  
22 experience, this gets easier, and this is a

1 committee that is really wrestling with some very  
2 difficult measures in an area where there are  
3 very few data, but it is critically important to  
4 get it right, so we all recognize how hard this  
5 has been today and thank you for that.

6 As you notice looking at the agenda,  
7 we are a little bit behind, but that is okay.  
8 NQF always seems to have a very aggressive plan  
9 for day one. However, in the interest of people  
10 getting to flights and keeping the anxiety in the  
11 room down just a little bit, since we don't have  
12 any measures on the docket to talk about anxiety,  
13 what I'd like to propose is that we keep  
14 breakfast available at 8, but if we could start  
15 15 minutes earlier and have people ready to go at  
16 8:15, we'll try to keep the introductory remarks  
17 short, and then we can move pretty quickly  
18 forward on the ASCO measures and then on the  
19 CAHPS measures and have everybody out on time, if  
20 not sooner.

21 So thank you all very very much, and  
22 Rachel, you have some other things to add,

1 correct?

2 MS. ROILAND: Just a few things. So  
3 I just want to echo Sean's thanks. I think all  
4 of us at NQF just want to say thank you for your  
5 sticking with us all day today. And just, like  
6 Sean said, we'll be starting at about 8:15  
7 tomorrow morning.

8 And then for tonight, though, we do  
9 have dinner reservations for the group at P.J.  
10 Clarke's, which is at 1600 K Street, and it's  
11 just about a block, block-and-a-half from here,  
12 so you probably do have time to go back to your  
13 hotel and walk there. The reservation is at  
14 5:45, so if you want to do that, you're more than  
15 welcome to just go there individually, or I'll  
16 walk a group over, if you just want to hang  
17 around here, I will walk you over around 5:45 as  
18 well, so it's -- we have about an -- well, little  
19 under an hour, so --

20 Did you have any questions?

21 MEMBER HANDZO: Tell me the address  
22 again.

1 MS. ROILAND: Sure. It is 1600 K  
2 Street, NW. And just tell them you're there for  
3 the reservation for Roiland and the National  
4 Quality Forum.

5 Well, we're actually down in the  
6 Sidecar. It's a special room downstairs, so we  
7 tried to treat you well and get you a special  
8 room, so P.J. Clarke's.

9 CHAIR MORRISON: So thank you  
10 everybody, and we will see everybody bright and  
11 early tomorrow morning.

12 (Whereupon, the above-entitled matter  
13 went off the record at 4:55 p.m.)  
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In the matter of: Palliative and End-of-life Care  
Steering Committee Meeting

Before: National Quality Forum

Date: 05-10-16

Place: Washington, DC

was duly recorded and accurately transcribed under  
my direction; further, that said transcript is a  
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