

NATIONAL QUALITY FORUM

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PERSON AND FAMILY CENTERED CARE PHASE 3

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TUESDAY  
JUNE 7, 2016

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The Committee met at the National Quality Forum, 9th Floor Conference Room, 1030 15th Street, N.W., Washington, D.C., at 8:30 a.m., Lee Partridge and Christopher Stille, Co-Chairs, presiding.

PRESENT:

LEE PARTRIDGE, Co-Chair

CHRISTOPHER STILLE, MD, MPH, FAAP, Co-Chair

BETH AVERBECK, MD, HealthPartners, Inc.

KATHERINE BEVANS, PhD, Children's Hospital of Philadelphia

SAMUEL BIERNER, MD, University of Nebraska Medical Center

REBECCA BRADLEY, LCSW, HealthSouth Corporation

JENNIFER BRIGHT, MPA, Momentum Health Strategies

DAVID CELLA, Northwestern University Feinberg School of Medicine\*

SHARON CROSS, LISW, Ohio State University Wexner Medical Center

DAWN DOWDING, PhD, RN, Visiting Nurse Service of New York\*

NICOLE FRIEDMAN, Kaiser Permanente

STEPHEN HOY, Patient Family Centered Care Partners

SHERRIE KAPLAN, PhD, MPH, University of California Irvine School of Medicine

LINDA MELILLO, MS, MA, CPHRM, CPXP, Spaulding Rehabilitation Network, Partners Healthcare System

LISA MORRISE, MA, Patient & Family Engagement  
Affinity Group, National Partnership for  
Patients

LENARD PARISI, RN, MA, CPHQ, FNAHQ, Metropolitan  
Jewish Health System

LISA GALE SUTER, MD, Yale School of Medicine,  
Yale Center for Outcomes Research &  
Evaluation (CORE)

PETER THOMAS, JD, Powers, Pyles, Sutter &  
Verville, P.C.

CARIN VAN ZYL, MD, FACEP, Keck School of  
Medicine of University of Southern  
California

**NQF STAFF:**

HELEN BURSTIN, MD, MPH, Chief Scientific Officer

KAREN JOHNSON, MS, Senior Director

ELISA MUNTHALI, MPH, Vice President, Quality  
Measurement

DESMIRRA QUINNONEZ, Project Analyst

KIRSTEN REED, Project Manager

SARAH SAMPSEL, MPH, Senior Director

SUZANNE THEBERGE, MPH, Senior Project Manager

**ALSO PRESENT:**

JACK FOWLER, PhD, Informed Medical Decisions  
Foundation

PAULETTE NIEWCZYK, MPH, PhD, UDSMR\*

KAREN SEPUCHA, PhD, Health Decision Sciences  
Center, Massachusetts General Hospital

MATTHEW WYNIA, MD, MPH, FACP, University of  
Colorado, Center for Bioethics and  
Humanities

\* present by teleconference

## T-A-B-L-E   O-F   C-O-N-T-E-N-T-S

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Adjourn

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

2 8:40 a.m.

3 CO-CHAIR PARTRIDGE: Good morning,  
4 everyone. This is Lee Partridge and Chris Stille  
5 and the NQF staff and the members of the PFCC  
6 Committee. We're all bright-eyed and bushy-  
7 tailed, ready to go to work.

8 I did want to mention just one little  
9 housekeeping thing this morning. I think I  
10 probably misinformed a couple of you yesterday  
11 who were talking of taking the subway to the  
12 Reagan Airport this afternoon. The Red Line,  
13 which is the line that's right around the corner  
14 from the Mayflower, the station right around the  
15 corner from the Mayflower Hotel, is single-  
16 tracking from 10 to 3 or something today, or  
17 maybe all day. Anyway, it's a mess.

18 And the simple and most direct thing  
19 to do is to walk out of this building, walk out  
20 of the elevator, go straight ahead, turn right on  
21 15th Street, walk down two blocks and you will  
22 come to a Blue Line Metro stop, which is called

1 McPherson Square. And you get on a Blue train in  
2 the direction of National Airport. And make sure  
3 you read the pylons so that you don't go the  
4 wrong way. You'll end up out in Maryland. And  
5 it's a straight shot and very easy. But please  
6 stay away from the Red Line.

7 Suzanne, I think, wants to just tell  
8 us one bit about the slides that you've got.

9 MS. THEBERGE: We just have a quick  
10 summary of what was decided yesterday. We  
11 thought we'd go over that briefly this morning  
12 before we got started. The Committee recommended  
13 Maintenance Measure No. 0420. And then the  
14 Committee also recommended the three CoreQ  
15 measures. Did not recommend the home and  
16 community-based services experience of care  
17 measure. Recommended three of the functional  
18 change measures, and did not reach consensus on  
19 two and did not recommend one. Those last three  
20 were the LTAC functional change measures.

21 And that's the summary of the  
22 discussion from yesterday. We had a great

1 discussion, lots of interesting things came up.  
2 And today we've got two measures on shared  
3 decisionmaking.

4 CO-CHAIR PARTRIDGE: Right. Then we  
5 will proceed to consider Measure No. 2962: Shared  
6 Decisionmaking. The developer is Healthwise.

7 Are they here with us? So if you'd  
8 like to come up and take a seat at the table.  
9 Good morning.

10 DR. FOWLER: Hi, I'm Jack Fowler and  
11 I'm with the Informed Medical Decisions  
12 Foundation, which is now part of Healthwise. And  
13 I'm here to propose a measure of the process of  
14 patient and provider interaction and the extent  
15 to which it meets standards for shared  
16 decisionmaking.

17 Just to give you a quick background,  
18 because it felt like a long time, the foundation  
19 started trying to get patients informed and  
20 involved in decisionmaking in 1989. And the way  
21 we started doing that initially was to create  
22 decision aids so we could get patients to the

1 point where they understood as much as their  
2 providers about the things that mattered in  
3 making a decision. We focused on preference-  
4 sensitive decisions; that is, where there was  
5 more than one reasonable option to deal with  
6 whatever problem they were dealing with.

7 And so we spent 15 years working on  
8 how to do that and doing it as well as we could.  
9 And at some point our board said, well, you've  
10 got to show that you're making the world better.  
11 We had tested individual things. There have  
12 actually been lots and lots of randomized trials,  
13 as you probably know, of good decision aids and  
14 how they impact people's knowledge, et cetera.  
15 But they wanted to know how we were doing more  
16 broadly. We wanted to change the world. And so  
17 we set out to see if we could document how  
18 decisions were being made and in a variety of  
19 places.

20 So, we hooked up with a group at the  
21 University of Michigan's Survey Research Center.  
22 And also there are some talented medical

1 decisionmaking folks there: Peter Ubel and Angie  
2 Fagerlin and Brian Zikmund-Fisher. And we did, I  
3 think, what was the first national survey of how  
4 decisions were made.

5 And so they did actually a random  
6 digit dial sample of adults 40 and older, and we  
7 asked them about 10 decisions that happen often  
8 enough that actually a sample of 2,500 would have  
9 a reasonable sample of them. So we had three  
10 cancer screening things that happen a bunch.  
11 That's mammography, PSA, colon screening. We had  
12 three meds. And then we had actually four  
13 surgical interventions on cataracts, hip/knee  
14 replacement and back surgery.

15 And one of the things we had to do to  
16 do that survey was to develop what do we want to  
17 know about a decision so we can characterize how  
18 the decision was made? And after talking to a  
19 lot of people, we ended up with three things that  
20 were sort of essential.

21 One is that patients need to be  
22 informed. So we had to measure whether or not



1       they understood the issues. Second is they had  
2       to have a meaningful interaction between provider  
3       and the patient so that the patient's voice had a  
4       chance of being heard in the decisionmaking  
5       process. And the last one is that ideally the  
6       decision itself would align with the goals,  
7       concerns, and priorities of the patient  
8       themselves when we got done with this process.

9               And so we worked -- this was 2007 and  
10       '08 -- to develop measures of all those things.  
11       And we did them first in the decision study. And  
12       we and others who worked with the foundation have  
13       been building on those measures ever since. And  
14       they are, I think, three different constructs and  
15       they each have to have their own measures and  
16       they each have a role to play.

17               So I'm going to talk about the process  
18       one. And we've been using that in several  
19       different settings. We have repeated the  
20       decision survey we did with Michigan and we've  
21       used it in a variety of places where we were  
22       studying how decisions were made. And one place

1 in particular that also gave us wisdom for what  
2 we're doing -- we hope it's wisdom -- we were  
3 also looking for sites in which we could see what  
4 it took to make shared decisionmaking a routine  
5 part of clinical care.

6 And we asked for volunteers of  
7 clinical sites around the country who'd be  
8 willing to make a special effort to try to make  
9 shared decisionmaking routine. And we picked --  
10 we actually ended up working with about 10 places  
11 around the country, in all kinds of settings, who  
12 would use decision aids when it was appropriate  
13 and who were committed to shared decisionmaking.  
14 And they became a kind of learning group for us.

15 And we collected a lot of data. One  
16 of the deals they had to make, we provided some  
17 support and they had to collect data as part of  
18 their commitment to us. And so we have a fair  
19 amount of data from them on all those topics:  
20 knowledge, alignment of decision, but also on the  
21 decisionmaking process. And so that's the  
22 background on which this measure came about.

1           We did not set out to build a measure,  
2           to create a measure of quality of clinical care  
3           per se. We had been working on how to  
4           characterize the kinds of decisions that patients  
5           make and the way they're made and whether they're  
6           made the way we'd like them to be made.

7           At some point we felt like we had  
8           enough data to say there's not another measure  
9           out there, that we know of, that if someone  
10          wanted to say, is this clinical site doing a good  
11          job of decisionmaking with their patients, I  
12          don't think there's another measure. And we  
13          decided we had enough data to make the case that  
14          this would be a reasonable approach to measuring  
15          that, if that's what you wanted to do. So that's  
16          why I'm here today.

17                 CO-CHAIR PARTRIDGE: Our lead  
18          discussants are Katherine Bevans, Jennifer  
19          Bright, and my colleague Chris. Which one of you  
20          wants to lead off? Jennifer?

21                 MEMBER BRIGHT: Okay, then.

22                 (Laughter.)

1           MEMBER BRIGHT: Just because I haven't  
2           had my first cup of coffee yet. That's why I get  
3           the top.

4           So, this is a new measure, and as Jack  
5           said, designed principally to demonstrate the  
6           value of a shared decisionmaking approach. So  
7           it's a process-focused measure. We focus on  
8           assessing the after-the-fact, after-care  
9           delivery, after the provision of a surgical  
10          intervention for one of seven surgeries, to  
11          assess what level of shared decisionmaking  
12          occurred.

13          Generally speaking, I was just reading  
14          back through the comments to make sure I captured  
15          everything, but I think Healthwise provides  
16          evidence using the Dartmouth Atlas and some other  
17          resources to provide evidence of value, why  
18          patients and providers would find this measure of  
19          value to demonstrate what shared decisionmaking  
20          looks like, which I think I -- I know I feel is  
21          certainly an important goal of developing a  
22          measure.

1           I think, just as an overarching  
2       commentary, some of the questions have to do with  
3       how such an instrument is implemented. So,  
4       issues around time lag and feasibility of  
5       implementation. I think there were some  
6       questions about how missing data is handled. And  
7       I know I had some questions about -- there were a  
8       lot of references to the impact of decision aids  
9       and how they boost a response of shared  
10      decisionmaking, and yet your instrument -- and I  
11      know we're not supposed to talk about the  
12      instrument necessarily -- but the instrument  
13      doesn't actually ask about decision aids, and  
14      neither does it ask about whether a patient is  
15      asked about their goals or preferences for  
16      treatment.

17           And so I'm curious as to why those  
18      things were omitted, when your evidence that  
19      you're presenting as rationale for doing this  
20      measure talks about how both of those things  
21      significantly boost a patient's sense of being  
22      involved in shared decisionmaking. So those are

1 the top line ones.

2 MEMBER BEVANS: So, just to add a few  
3 things. I would like to revisit and kind of echo  
4 what Jennifer said, in part because it was a  
5 comment that was a comment that was I think made  
6 in public comment about the omission of direct  
7 assessment of people's treatment goals and the  
8 degree to which the treatment actually addresses  
9 those goals. So, just to come back to that maybe  
10 in our discussion of importance.

11 But I just wanted to make sure that I  
12 understand fully that the measure itself is  
13 comprised of four items, I believe, and there's  
14 one that's sort of interchangeable based on the  
15 condition.

16 DR. FOWLER: Yeah, it is four items.  
17 It depends a little bit on the decision as to  
18 sort of how many options there are, is kind of  
19 the best way to phrase it. So we have two ways  
20 of asking the question about options presented.

21 MEMBER BEVANS: Okay. And then each  
22 item is scored zero to one, in some cases

1 dichotomizing a Likert scale. And then the  
2 measure, it's a sum of those. I'm just kind of  
3 confirming so we're on the same page. But the  
4 measure is the sum of those four item scores and  
5 then be aggregated by calculating the average at  
6 the provider level. Right?

7 DR. FOWLER: Yeah, they're two yes/no  
8 items which are one/zero items. And there are  
9 2/4 response alternative items that we  
10 dichotomize, as you say, and you get a point if  
11 you gave one of the top two answers and you don't  
12 get a point if you gave the bottom two answers.

13 MEMBER BEVANS: Okay. So lastly,  
14 again, before we get into the specific criteria,  
15 the information that you have to present to the  
16 Committee today is based on studies done with 266  
17 patients, is that correct, from four sites with  
18 multiple treatment decisions or conditions in  
19 each of those sites.

20 DR. FOWLER: I noticed that comment  
21 about, are we leaving out multiple decisions, and  
22 you've got to ask these questions one decision at

1 a time.

2 MEMBER BEVANS: Yeah, I just wanted to  
3 confirm --

4 (Simultaneous speaking.)

5 DR. FOWLER: And mostly these are, you  
6 know, if you're thinking about having your knee  
7 replaced, you may be doing some other stuff, but  
8 that's probably the biggest thing in your mind.

9 MEMBER BEVANS: I just wanted to  
10 confirm the data that are presented that are  
11 those 266 patients, is that right?

12 DR. FOWLER: They vary by the topic.

13 MEMBER BEVANS: Right. Total, though?

14 DR. FOWLER: Right.

15 MEMBER BEVANS: Okay.

16 CO-CHAIR STILLE: Great. Thank you.

17 And I'm excited to see a measure on shared  
18 decisionmaking, because I think, from a policy  
19 standpoint, there's really very, very little out  
20 there and I think anything that we can do to move  
21 things along is good.

22 I had a couple of questions. The



1 first is that the level of measurement, the level  
2 of reporting, is this meant to be kind done at  
3 the provider level, or what's your sort of intent  
4 with this?

5 DR. FOWLER: Yeah, I mean, what we're  
6 doing is -- obviously, most of the work we did  
7 was at the individual level, and that's where we  
8 did thousands of interviews and all that stuff.  
9 But I think we have enough data to show that you  
10 can do it at a clinical site level. And you  
11 could do it at a clinician level, if you had the  
12 data.

13 And basically what we did here was  
14 pull together what we have from different sources  
15 to say, can we make the case that if you do it as  
16 a way of assessing the clinical care patients  
17 got, that you can get a meaningful answer?

18 And we thought that -- one of the  
19 challenges, as you've probably all wrestled with,  
20 when you're to validate something that you can  
21 actually say that we're measuring better clinical  
22 care, whatever that means, you've got to have a

1 theory about, well, how would you know that they  
2 were doing something clinically that ought to  
3 show up?

4 And we thought that these sites that  
5 we're working with that are committed to shared  
6 decisionmaking were -- well, it was reasonable to  
7 say these people were trying to do shared  
8 decisionmaking more than the average person. And  
9 so saying that this measure showed up differently  
10 and more highly in those sites than they did in  
11 other places of usual care seemed like a  
12 reasonable body of evidence that this was a valid  
13 measure of clinicians doing the right -- doing  
14 this kind of thing better.

15 CO-CHAIR STILLE: Okay. I kind of  
16 wanted to know where to look for variability,  
17 whether it was within providers or among, between  
18 providers, for example.

19 Okay. Right. It's seven common  
20 procedures. Being a pediatrician I always say,  
21 all right, we can use more pediatric measures,  
22 but obviously the limitations are what they are

1 with those procedures.

2 This is kind of getting into validity,  
3 and maybe I'll mostly save this for that, but  
4 they were all people that had the procedure. And  
5 so it excludes people that didn't have the  
6 procedure. And I wanted to kind of know just  
7 some information about why you did that. I think  
8 I can maybe guess, but I'd like to --

9 DR. FOWLER: Yeah, well, that's one of  
10 the things I wanted to talk about, was the  
11 selection of the procedures and the patients and  
12 why not.

13 CO-CHAIR STILLE: Right.

14 DR. FOWLER: And one of the biggest  
15 problems that we have found, and it comes from  
16 our work with the shared decisionmaking sites  
17 that we've been working with, is identifying  
18 people, reliably, who faced a decision and didn't  
19 do anything. It turns out to be virtually  
20 impossible. They do not document. I mean, you  
21 can go in and have a conversation about your  
22 knee, and if walk out and go to physical therapy,

1       there's not necessarily anything that anyone  
2       could ever find that says you did -- we are most  
3       interested -- we kind of have a bias that thinks  
4       that the people who didn't get the intervention  
5       are the successes, in some cases.

6                   CO-CHAIR STILLE:   Sure.

7                   DR. FOWLER:   But we cannot figure out  
8       a way reliably to identify those people.  And if  
9       you're going to have a measure of clinical care  
10      and how a particular site does it, you have to  
11      have a reliable way of getting the same  
12      population of patients who've had the same  
13      experience.

14                   So the only thing I know that I can do  
15      reliably is, if they cut them, it will be in the  
16      record and then you can survey them.  And I'm  
17      willing to make the case that those are the  
18      people you -- ethically, you want to particularly  
19      make sure -- you'd be particularly interested in  
20      what kind of decisionmaking process people who  
21      actually have intervention had.  I think there's  
22      a case to say that that is a particularly group

1 in that respect, though I would love to -- and  
2 maybe the future will bring a better way of  
3 recording things so we can do a better job.

4 The other thing, of course, we are  
5 always looking for is a lot of the interventions  
6 I would like to include here, sometimes it's hard  
7 clinically to make sure you can identify the  
8 people who actually have a choice. So we tried  
9 to get the ones where we thought most of these  
10 really did have an alternative that a reasonable  
11 person would follow. Whereas, some others, some  
12 clinical things can complicate it and it's  
13 trickier.

14 And, again, one of my goals was to  
15 say, can we identify a set of people that, one,  
16 we are confident should have had a choice? So, a  
17 rational person could have gone more than one  
18 way. And, two, that we can reliably identify  
19 across different sites so we're comparing the  
20 same kinds of patients from clinical site to  
21 clinical site, which seems is sort of essential  
22 if you're going to use it as a measure of quality

1 of care.

2 So that's sort of how we got here.  
3 It's not perfect, but it seemed like a pretty  
4 good start.

5 CO-CHAIR STILLE: Great. Thanks.  
6 Those are kind of my major points. Thanks.

7 MEMBER FRIEDMAN: I have a question  
8 about potential people excluded. So would this  
9 include patients that can't speak for themselves  
10 when it comes to shared decisionmaking?

11 DR. FOWLER: Yes, it would exclude  
12 them. It just seems like the dynamics are just  
13 going to be quite different for those folks. And  
14 I would hope that there's a process for them, but  
15 it just seems like (audio interference) --

16 CO-CHAIR PARTRIDGE: Peter?

17 MEMBER THOMAS: Forgive me for being  
18 late this morning, but I read the material and  
19 I've listened to the conversation I was here for.

20 I totally understand the importance of  
21 -- that the measure and what it's kind of looking  
22 at. What I'm wondering if you could elaborate on

1 is the nexus between being involved in the  
2 decisionmaking process and actually improving  
3 care, improving quality. So that's the -- I see  
4 that you've got in the evidence section a study  
5 of 2,800 patients and the like, but could you be  
6 a little bit more specific about the link between  
7 the two?

8 DR. FOWLER: Yeah, I mean, that case  
9 has been, I think, building in a lot of different  
10 circles, including NQF. I think if you go on  
11 their website they say shared decisionmaking is a  
12 good thing. But I the notion -- that we started  
13 thinking shared decisionmaking was a good thing,  
14 as someone mentioned, from the Dartmouth Atlas  
15 data years ago, where you see these wide  
16 variations from area to area that have got to be  
17 physician-driven. They're not patient need or  
18 patient preference. We have pretty good data on  
19 that.

20 So the argument that a patient, an  
21 informed patient involved in the decision should  
22 be a part of the decisionmaking, I think, comes

1 part out of that.

2 The evidence about whether it's --  
3 actually Karen Sepucha is going to be your next  
4 guest and has worked quite a bit on showing that  
5 shared decisionmaking makes decisions better.  
6 And that really has to do with how can you tell a  
7 better decision when you see one, which is not  
8 absolutely easy. I can say it really easily.  
9 You want the one that aligns with the patient's  
10 goals, preferences, and priorities. And that  
11 seems like a really great idea until you start  
12 writing the equation. And we've collected lots  
13 of data on what people care about and what  
14 they're concerned about.

15 And then it turns out that some people  
16 will make the decision based on one thing. It's  
17 not that they totaled up the pluses and minuses  
18 to do that. So we've had some difficult -- and  
19 we've asked people to summarize. That's another  
20 way to find out did you get a good decision.  
21 Would you do the same thing again? How would you  
22 rate the decision? And you do get some



1 relationships between involving patients and how  
2 they feel about it. But, again, if they're not  
3 informed, for example, they can be pretty happy  
4 with a decision that probably doesn't make much  
5 sense.

6 So I think there's an ongoing need for  
7 more data about the relationship between the  
8 interaction between provider and patient and the  
9 net result, whether you get better health out of  
10 that, whether you get happier patients, whether  
11 you get better aligned decisions. I think that's  
12 still got to be a work in progress. And we  
13 haven't solved that problem yet.

14 I do know that if people aren't  
15 informed and they're not involved, then the  
16 patient voice won't be heard, and that doesn't  
17 seem like a good thing. That's the best I can  
18 do.

19 CO-CHAIR STILLE: Sorry. Just two  
20 quick technical things: the people on the phone  
21 are having a hard time understanding, so please  
22 speak directly into your mic. If you can hear

1       yourself through the loudspeaker, chances are  
2       this is good.

3               The other thing is a couple people  
4       have their cell phones close to the mics and  
5       there's some interference. So just have your  
6       cell phone a couple feet away. Thanks.

7               CO-CHAIR PARTRIDGE: Ready to move  
8       onto evidence? Sorry. Lisa?

9               MEMBER SUTER: So I just wanted to  
10      comment. As a measure developer, this and the  
11      next measure are actually measures where I want  
12      to disclose that I'm not working on a measure  
13      related to this, but I am working on a measure of  
14      informed consent for CMS, which is tangential to  
15      what we're talking about. It in no way overlaps  
16      with what -- it's not a patient-reported outcome  
17      measure, but I wanted to disclose that  
18      information and defer to the chairs on whether or  
19      not I should vote.

20              But the other thing I wanted to notify  
21      you is that, in our conversations with patients  
22      about the informed consent process, if they are

1       so eager to have us ask information about this,  
2       it's incredible. They are pushing for this kind  
3       of measure. They are pushing for us to ask.  
4       It's really -- you can't speak to patients about  
5       this process without them wanting us to go  
6       further than what we're doing.

7               So I just wanted to comment on the  
8       value of asking these questions and defer to you  
9       guys on whether or not I should vote. I can give  
10      you more specifics about the measure.

11              CO-CHAIR PARTRIDGE: The comments to  
12      my left were you're fine.

13              MEMBER KAPLAN: Yeah, I have a similar  
14      disclosure. I've known Dr. Fowler for decades,  
15      an undisclosed number of decades.

16              (Laughter.)

17              MEMBER KAPLAN: And I also have a --  
18      I've developed for the medical outcomes study a  
19      global measure of participatory decisionmaking  
20      style. I was not involved in either of these two  
21      measures and haven't, sadly, working with Dr.  
22      Fowler for now probably more than a decade,

1       either, but I just wanted to make sure everybody  
2       knew that. And I'm happy to recuse myself if  
3       there are issues of conflict.

4               CO-CHAIR PARTRIDGE: All right. Onto  
5       the first threshold question: evidence. And any  
6       comments on that topic before we proceed to a  
7       vote?

8               All right. Desi?

9               MS. QUINNONEZ: We are not voting on  
10       Measure 2962, Shared Decisionmaking. Voting is  
11       now open for evidence. Rationale supports the  
12       relationship of the health outcome, or PRO, to at  
13       least one healthcare structure, process,  
14       intervention of service. Option No. 1 is yes,  
15       option No. 2 is no.

16              We're looking for one more vote.

17              MS. THEBERGE: David, we need your  
18       vote. Can you submit it via the chat? Thank  
19       you.

20              MS. QUINNONEZ: All votes are in and  
21       voting is now closed. The results read 100  
22       percent yes, 0 percent no.

1                   We're now voting for performance gaps.  
2       Well, wait.

3                   CO-CHAIR PARTRIDGE:   The next item  
4       under evidence is that one: gaps, et cetera.   Are  
5       there comments?   Chris?

6                   CO-CHAIR STILLE:   There does seem to  
7       be a good gap and a reasonable score  
8       distribution.   It's interesting to point out that  
9       the hospitals that you've been working with,  
10      since they're interested in this, may even be the  
11      best of the best.   So I would think if there is  
12      any bias from having relatively small numbers, it  
13      would be in the direction where you'd actually  
14      see more variability among other hospitals.   So  
15      even though the numbers are small, I felt that  
16      they were pretty good.

17                  MEMBER DOWDING:   Hi, it's Dawn on the  
18      phone.   Can I just ask -- I just have a quick  
19      question, if that's okay?

20                  CO-CHAIR PARTRIDGE:   Go right ahead.

21                  MEMBER DOWDING:   It's just really to  
22      ask about the issue to do with the health

1 literacy of the patients who've used the tool. I  
2 mean, I've looked at the samples and there's  
3 very, very small numbers of people who are in  
4 ethnic minorities. And I just wondered if there  
5 have been any account made for the health  
6 literacy of the patients are in the tool?  
7 Because there is some research to suggest that  
8 health literacy is actually related to an ability  
9 to be involved in decisionmaking. I mean, it's  
10 just a query really on whether or not the  
11 developers have got any ideas about how to deal  
12 with that.

13 DR. FOWLER: Actually, that's a topic  
14 we worried about a lot. And you're right that --  
15 I mean, the data we have, particularly in the  
16 sites, are not as heterogeneous as you might  
17 want. It just turns out that's the patients they  
18 treat. I can't do anything about that. But we  
19 really have looked very hard, for example, at --  
20 I mean, the hypotheses that people would have  
21 would be that these were people with less formal  
22 education, people who are older. That's another

1 group of people like me. How would folks like  
2 that want to participate, and ethnic minorities?

3 And we have found very, very little  
4 evidence that that's true. And there's at least  
5 one published paper where we tested -- we didn't  
6 have ethnic minorities in that, but we had pretty  
7 good samples of low education people and older  
8 people, both about how important they thought --  
9 one, how much they learned from decision aids;  
10 and two, how important they thought it was to be  
11 involved and informed in decisionmaking. And  
12 there absolutely was no difference.

13 In fact, older people, they benefit a  
14 little bit more, because less educated people  
15 started out with less information. So they  
16 benefit more from efforts to make the  
17 interactions informative. They actually raised  
18 their level of knowledge a little bit. And they  
19 respond really positively.

20 There may be some groups around, I  
21 mean, we've been hearing that don't want to share  
22 in decisionmaking and want to leave it to the

1 doctors, but we just keep finding that that's a  
2 stereotype. And I'm not saying that if you don't  
3 have -- you know, one of the things that's really  
4 important is to have sources of information that  
5 are well-structured for people and don't make  
6 assumptions about their literacy levels and their  
7 prior information. And that's a really important  
8 part of getting information in the right form.

9 But as far as participating, we just  
10 have not been able to find evidence that there is  
11 resistance to participating in any particular  
12 group.

13 CO-CHAIR PARTRIDGE: Katherine?

14 MEMBER BEVANS: That's very  
15 interesting, first of all, your comments about  
16 that. So, thank you.

17 In thinking about gap, one point that  
18 you note in your report is that there is -- it's  
19 not quite a ceiling effect -- but a higher mean  
20 for a particular group; that is, those who have  
21 undergone surgery or are considering surgery for  
22 lower back pain. Which sort of makes sense, and



1       you justify that by saying there may be less of a  
2       choice in that situation.

3               DR. FOWLER:  Actually, I don't think  
4       so.  I was surprised a little bit, but back is  
5       actually a surgery -- when you talk to orthopedic  
6       surgeons, in particular, they're worried about  
7       back surgery.  And the majority of people who  
8       have back pain I think are not amenable and don't  
9       benefit from surgery.  And so I think they work  
10      pretty hard to make people know the pros and  
11      cons.  At least, most of them do.  I'm pretty  
12      convinced that that's kind of real.

13              And so I didn't -- you know, and of  
14      the 10 procedures that we did -- or 10 decisions  
15      that we did in the decision study, the backs were  
16      by far the best.  And so I think that's probably  
17      real, as best I can tell.

18              MEMBER BEVANS:  Okay.  Yeah, so I  
19      guess the more general question for me is, as you  
20      pointed out, the questions are really most  
21      pertinent to people in situations where there is  
22      a surgical intervention for which there is an

1 option, right? You have either the option to,  
2 yes or no, you know, complete the intervention,  
3 or there are multiple choices.

4 So I guess I'm wondering for this  
5 measure whether that is a component of your  
6 specifications, that it may be most appropriate,  
7 or really only appropriate under certain  
8 circumstances, or whether you with the measure  
9 intend to provide any guidance around that point,  
10 sort of who it's appropriate for, who it may not  
11 be.

12 DR. FOWLER: Yeah, I mean, I want to  
13 make a distinction between who I think it's -- I  
14 think shared decisionmaking is appropriate for  
15 just about everything. I mean, I'm a bit of  
16 devotee about that. We picked these because,  
17 some combination of we thought that we could  
18 reliably sample people who had made a decision,  
19 and therefore for whom the shared decision model  
20 was definitely appropriate, and for which we had  
21 data.

22 I mean, for example, I would love to

1 figure out a way to do this for mammograms, for  
2 PSA testing, for taking statins. I mean, there  
3 are lots -- of taking depression meds, having  
4 cataract surgery. There are lots and lots of  
5 decisions that I'm pretty sure are overused and  
6 where having a standard of shared decisionmaking  
7 should be routine. I just either didn't have the  
8 data or was worried about being able to identify  
9 the decisionmaking moment.

10 Pills, for example, are really a hard  
11 one because it's sort of an ongoing thing. And  
12 did you have a decisionmaking visit and did it  
13 meet standards this last time? But you've got to  
14 sample it. Trying to sample across some period  
15 of time gets really confusing about answering  
16 questions.

17 So I hope this keeps growing and we  
18 find more and better ways to use these questions,  
19 but this seemed like a start.

20 CO-CHAIR PARTRIDGE: Stephen?

21 MEMBER HOY: Yeah, forgive me, I don't  
22 know where this comment falls in the process, but

1 I'm going to throw it in here. And I mirror  
2 Chris' excitement to see a shared decisionmaking  
3 measure come up. But my biggest concern -- I'm  
4 looking for you to ease my concern -- is that the  
5 priorities and goals of the patient influence the  
6 shared decisionmaking, and that, to me, good  
7 shared decisionmaking is when the provider and  
8 the patient have access to the same information.

9 So that means that my goals and  
10 priorities are understood by my clinician who  
11 helps me make that decision. And patient  
12 education, knowledge, information around their  
13 decision is an important piece of that, but I  
14 would like to see somewhere where the priorities  
15 are engaged by the clinician. And that may be at  
16 another level, but, again, I'm just looking for  
17 some information around that.

18 DR. FOWLER: Okay. Great. I  
19 absolutely couldn't agree with you more that  
20 having the patient's goals and concerns and  
21 priorities and preferences on the table in part  
22 of the decisionmaking process is the best. The

1 best decisionmaking I know about was done at  
2 Dartmouth in the breast cancer center where the  
3 woman would see a decision aid and then she would  
4 actually fill out a questionnaire about her  
5 goals, concerns, and priorities that would go to  
6 the physician. And that would be part of the  
7 conversation that they had. And when you when we  
8 get the round trips all set up with the medical  
9 records and we're collecting data like that on a  
10 routine basis, maybe we'll have the goals and  
11 concerns integrated routinely in that way. And I  
12 think that would be fantastic.

13 We didn't happen to have the goals and  
14 concerns question in the initial set of  
15 questions. We asked about the process. And I  
16 mused about that some. And I've got a lot of  
17 data that don't have that question in it, so  
18 that's why it's not there.

19 I kind of think that -- I think making  
20 sure you ask the patient what the patient wants  
21 and have a discussion of the pros and cons -- you  
22 would hope discussion of the pros and cons would

1 be a time when the goals and concerns would get  
2 on the table as part of it. It's a crummy  
3 discussion if it's the doctor talking at the  
4 patient. Then it won't achieve that, and then  
5 all we've got is the patient expressing what they  
6 wanted if they did that. I think it's an  
7 essential part. We also -- parsimony was kind of  
8 on our mind, and short seemed like it was better.

9 So I would love it if you'd go out  
10 tomorrow, add that question, and collect some  
11 more data and see how much it adds and whether it  
12 would be characterized. I think it would be  
13 super. It absolutely fits the model and it could  
14 absolutely have been there. So I don't push back  
15 about it at all. You don't have it because  
16 that's not the way we collected the data, so I  
17 can't do that today. But it's key and it should  
18 be part of it.

19 CO-CHAIR PARTRIDGE: Okay. Katherine,  
20 do you still have a comment?

21 All right. Are we ready to vote on  
22 gap, et cetera? You think so. Desi?

1 MS. QUINNONEZ: We're now voting for  
2 performance gaps on Measure 2962, data  
3 demonstrated considerable variation or overall  
4 less than optimal performance across providers  
5 and/or population groups. Option No. 1 is high;  
6 option No. 2, moderate; option No. 3, low; and  
7 option No. 4, insufficient.

8 Looking for one more vote. Okay.  
9 All votes are in. Voting is now closed. The  
10 results read 53 percent voted high, 42 percent  
11 moderate, 5 percent voted low, and 0 percent for  
12 insufficient.

13 CO-CHAIR PARTRIDGE: Dr. Fowler, I  
14 think people like this measure.

15 (Laughter.)

16 CO-CHAIR PARTRIDGE: I have to say  
17 that I have had a little bit of -- I've had an  
18 opportunity to work a little bit with you and  
19 talk with your colleagues about shared  
20 decisionmaking, with particular reference to C-  
21 sections, and it's always a pleasure to work with  
22 you all.

1                   And we are now going to move on to a  
2                   discussion of reliability and validity, our old  
3                   friends, and scientific acceptability. So  
4                   comments? Katherine?

5                   MEMBER BEVANS: First of all, I want  
6                   to note that your work on reliability, in  
7                   particular the observations, is really, I think,  
8                   wonderful, and I wish we'd see more of that in  
9                   measures that are presented here where there are  
10                  external coders looking at tapes of actual  
11                  interactions between patients and clinicians and  
12                  verifying whether or not a person's report of  
13                  that process is a reliable report. I think that  
14                  really strengthens the case for its reliability.

15                 As you note, of course, at the  
16                 provider level the reliability coefficient is  
17                 somewhat low. And you note that that could be  
18                 related to sample size, but that's something that  
19                 hopefully will be mitigated with some more data.

20                 CO-CHAIR STILLE: And, yeah, I'd like  
21                 to echo what Katherine said. I think if this  
22                 were to go so far as to be benchmarking providers



1       against one another, or institutions against one  
2       another, we'd probably need a lot more sort of  
3       large-scale data, but for the moment I think what  
4       you have is good.

5                   CO-CHAIR PARTRIDGE:   Sherrie?

6                   MEMBER KAPLAN:   Yeah, Jack, that was  
7       actually my question.  If this is supposed to be  
8       used at the provider level and you only have six  
9       -- it looks like six clinical sites, even though  
10      they're all around the country -- if this is  
11      intended ultimately to be used at the provider  
12      level, you'd want to do an intra-class  
13      correlation coefficient looking at between versus  
14      within provider variability, just to make sure  
15      that there isn't a lot of noise internal to these  
16      sites being measured.

17                   So is that the plan?  Or how do we  
18      evaluate?  Because one of the measures coming up  
19      is a clinical measure to be used at the site  
20      level.  This is supposed to be considered at what  
21      level?  So we're at the patient level or --

22                   DR. FOWLER:   Well, I mean, I think

1       whatever site -- I mean, I think any delivery  
2       unit that you've got data for -- I think you can  
3       do it for a clinic, which might be a bunch of  
4       providers who did a thing, or an ACO. Or if you  
5       had enough cases, you can do it at the provider  
6       level. I think it can be -- we only had the data  
7       we had, and so that's why our samples are small.  
8       And we had to have them doing, obviously, the  
9       same procedure.

10               So we actually had a lot more  
11       patients, but in order to get replicates --  
12       enough patients and providers where we could make  
13       replicates, and then look at the correlations  
14       when you had samples both -- we had what we had,  
15       and it wasn't overwhelming, as Christine said.  
16       But I hope we're going to collect more. We're  
17       trying to use this every chance we get.

18               MEMBER KAPLAN: So, Sarah, this is  
19       another one of those ones where a phased approval  
20       process, you know, this is a new measure in  
21       development, this is a more progressive measure.  
22       And as you keep going, you'd expect more of it

1 and more data to come out, but help us in the  
2 group sort of understand where -- this is clearly  
3 a new measure. It's something that is going to  
4 have and need more testing before it's used at  
5 different levels. But where are we with that  
6 issue?

7 DR. FOWLER: Yeah, I mean, we haven't  
8 been mainly using it to evaluate clinical sites,  
9 so we had to use data that we had that we  
10 collected for other kinds of purposes. So that's  
11 where we are at the moment.

12 MS. SAMPSEL: And NQF does not have a  
13 phased approach. So it's either -- and I would  
14 draw you back, though, towards previous  
15 discussions, previous decisions. We are at a  
16 point where we're facing new measures, and we're  
17 facing novel measures that we haven't seen  
18 before. And so I do think NQF is still grappling  
19 with how we're going to deal with that.

20 One of the things -- and we can talk  
21 about it a little bit later -- a totally separate  
22 project on shared decision aids that NQF that is

1 funded for right now, but that doesn't help you  
2 here. So I guess what I would encourage you all  
3 is to think about kind of the results as they  
4 were, your past decisions on other measures with  
5 similar types of data. And these are also things  
6 that, you know, they go into the report and we'll  
7 constantly be watching.

8 But I would say, you know, when Jack  
9 comes back in a year with an annual update, and  
10 then in three years for maintenance review, the  
11 review process gets a whole lot tougher because  
12 we're going to want more of that data.

13 CO-CHAIR PARTRIDGE: Jennifer?

14 MEMBER BRIGHT: I'm going to betray  
15 how long it's been since I've been in grad school  
16 statistics class, but is there any importance to  
17 the number of responses that would be considered  
18 important to have a reliable score? You don't  
19 really speak to that, but since we're talking  
20 about sample sizes, like applications, measure,  
21 how many responses are really needed in order for  
22 it to be a meaningful representation of what's

1 going on in the practice? And because of that,  
2 how can you compare practices?

3 Because let's not kid ourselves, this  
4 is important, at its core, for internal practice  
5 improvements, but we all know everybody will  
6 still look at it and say, how can you judge best  
7 approach, right? So is there an N that has to be  
8 met? Is that in your specifications?

9 DR. FOWLER: Well, I took a stab. As  
10 you know, the sample size thing is about what  
11 your standard errors are and then how confident  
12 you'd be that the differences that you observe  
13 matter, are big enough. And so, it looks like --  
14 and it somewhere in the 50 pages there.

15 But if you look at the standard errors  
16 around these things, it's actually not that big.  
17 And if you had samples in the 50 to 100 range and  
18 you looked at how much difference we were  
19 observing between places that looked like they  
20 were doing it pretty well and usual care, that  
21 you would probably pick that up most of the time.

22 So I think that I feel comfortable

1 saying that, for what we're talking about, that  
2 getting 75 to 100 responses would be a good  
3 thing. And I actually -- one of my -- we are  
4 talking -- it's on my list of things that people  
5 asked about -- and maybe it's some other section,  
6 but I actually, of course, think non-response may  
7 be a bigger deal than sample size in this world  
8 these days.

9 I'm really worried about non-response  
10 everywhere and how the self-selection that shows  
11 up when your response rate is 25 percent -- who  
12 those 25 percent are and what's on their minds.  
13 It's different from the other 75 percent. And I  
14 think that's a big deal for almost any patient-  
15 reported measure.

16 So if I were going to spend my money  
17 on data collection, I'd take my 75 and then try  
18 to get as good a response rate as I could to  
19 generate that 75 as compared with going about  
20 getting a sample a little bigger. That's sort of  
21 where I am.

22 But I think the standard errors look

1       like 75 to 100 will detect clinically meaningful  
2       differences between places that aren't doing a  
3       very good job and places that are. And that  
4       seems like the key issue.

5               CO-CHAIR PARTRIDGE: If there are no  
6       further questions, are we ready to vote on  
7       reliability? Desi?

8               MS. QUINNONEZ: Voting is now open for  
9       the reliability of Measure 2962, reliability  
10      including precise specifications and testing.  
11      Option No. 1 is high; option No. 2, moderate;  
12      option No. 3, low; and option No. 4,  
13      insufficient.

14              Okay. Looking for one more vote.

15              All votes are in and voting is now  
16      closed. The results read 11 percent voted high,  
17      74 percent voted moderate, 16 percent voted low,  
18      and 0 percent insufficient.

19              CO-CHAIR PARTRIDGE: Okay. Moving on  
20      to validity. Comments? Katherine?

21              MEMBER BEVANS: Since you brought it  
22      up, response rates. Could you tell us a little

1 bit about how that played out in these data?  
2 Because I didn't -- maybe I missed it, but I  
3 didn't see it in the report. And I never know  
4 whether to bring up response rates as part of  
5 validity, as a threat to validity or feasibility,  
6 but here it is.

7 DR. FOWLER: Yeah, and there's a  
8 range. And the reason you didn't have them is  
9 because all these different data sets and  
10 response rates are different everywhere.

11 The two national surveys -- the trend  
12 survey, it was based on a panel. It was high,  
13 but they were already in a panel, so that doesn't  
14 -- I mean, like, they were 85 percent or  
15 something. But the key ones are the ones on the  
16 clinical sites. And they had a range from 25 to  
17 60 percent. And we talked about one of the  
18 things that maybe you wrote in terms of, what are  
19 the issues about how do you collect data and what  
20 do you do?

21 And there's no doubt that, one, how  
22 clinical sites sort of present that they care



1 about getting this back. If somebody actually  
2 handed something to somebody and said, "we read  
3 it" or "we're going to send you a questionnaire  
4 about things and it would really be helpful if  
5 you'd send it back," that really helps. And to  
6 follow up and say, "could you send it back?"  
7 helps, too. And some places really care about it  
8 and they do better and some places aren't.

9 The average CAHPS survey these days is  
10 27 percent. I think almost all the data -- I  
11 think all the data that's represented -- there  
12 might have one 23 percent or something -- but I  
13 think all the day that's represented in here are  
14 in that ballpark. And the average is higher than  
15 that, but it's all over the place, to be fair.  
16 And I don't know. I can't tell you exactly how  
17 the answers would have been different if the  
18 response rates were higher. Again, sorry. But  
19 it's a good question.

20 CO-CHAIR PARTRIDGE: Jennifer?

21 MEMBER BRIGHT: I know this is  
22 problematic, too, but you yourself said that the

1 response pool was pretty homogenous, old white  
2 men. And except for the breast cancer, right?  
3 Good point.

4 DR. FOWLER: Yeah, and the mastectomy,  
5 by the way --

6 (Laughter.)

7 MEMBER BRIGHT: But it does bring up  
8 the point -- I think one of the big questions  
9 that everybody has is, okay, shared  
10 decisionmaking is still a pretty novel concept,  
11 and how do you develop a process to do it well  
12 and then measure its impact? But we also know  
13 that there's a high level of disparities in  
14 decisionmaking, in communication, language  
15 barriers, all those things, not just health  
16 literacy.

17 So, you know, what did you examine  
18 about that? Is there anything that needs to be  
19 talked about in terms of how valid these results  
20 are given that it was such a homogenous  
21 respondent pool?

22 DR. FOWLER: Yeah, I mean, the sample

1 about being old white men, that was only 65  
2 percent men. That's a lot of men, I agree. But  
3 it did have two of the procedures, too, as well  
4 as the sites. And we need to expand this kind of  
5 measure to the decisions that all kinds of people  
6 make. Clearly, actually, pregnancy-related  
7 decisions are ones where you get -- with a  
8 different population, for example.

9 MEMBER BRIGHT: Yes.

10 DR. FOWLER: And that's a place where  
11 people are working hard on having more informed  
12 and involved decisions about C-sections and  
13 induced deliveries and things like that. So, as  
14 I say, I mean -- and we have collected data, as I  
15 say, on other topics, but not in the form that I  
16 could present them to support the validity or  
17 where I thought we could reliably get people.

18 So there's nothing conceptually about  
19 why these questions shouldn't work. And we have  
20 collected the data, as I say, about mammography  
21 and statins and stuff where you get really  
22 different samples. So I don't think there's any

1 reason to worry that they don't work to capture  
2 what people have to say.

3 And by the way, the coding studies  
4 where we had coded the interactions and compared  
5 them to the response answers, those were done  
6 with breast cancer. So that was a different  
7 population, too.

8 So I don't think there's any reason to  
9 think that these questions don't capture well  
10 what the interaction is between providers and  
11 patients of a variety of sorts. There may be --  
12 I mean, I can't do -- I don't have the data, for  
13 example, about people with different languages  
14 and stuff like that, and that's -- I don't know  
15 where that is, but I think mainly I'd -- I think  
16 I'd have -- I feel pretty comfortable that they  
17 -- that there's not a basis for saying these  
18 questions only apply to -- or mainly work best  
19 with white guys who are making orthopedic  
20 decisions. I don't think that would be unfair.

21 And for example, PCI is one we're  
22 talking about, and those are among the worst

1 decisions anywhere. I mean, those patients have  
2 no clue what's going on. And those are a lot of  
3 white guys. There's some women, too.

4 CO-CHAIR PARTRIDGE: Lisa?

5 MEMBER SUTER: I saw you did a lot of  
6 work in development with patients. Did you take  
7 this back to patients after completing it and ask  
8 them their opinions or have you presented the  
9 results to patients at the end of the process?

10 DR. FOWLER: Have we taken results  
11 from process scores and fed them back to patients  
12 and said what do you think about --

13 MEMBER SUTER: That and the questions  
14 that you finally came up with. Have you shown  
15 those questions to patients and asked them --

16 (Simultaneous speaking.)

17 DR. FOWLER: Well, we did do a lot of  
18 cognitive testing of questions. That's sort of a  
19 routine part of what we do. And at least what  
20 that means for us is asking people questions,  
21 having them answer the questions and then talking  
22 to them about how they understood the questions,

1 talking to them about how they arrived at the  
2 answers that they had and whether or not -- and  
3 working with them about whether the answer  
4 reflected what it is they had to say about that.  
5 That's not saying whether -- that's not the same  
6 as question -- as whether they care whether the  
7 answer is, but at least we had a lot of patient  
8 input in terms of the design and the selection of  
9 particular questions that we did.

10 I don't have feedback -- and I don't  
11 know if it was your comment, but there was a  
12 comment, or maybe more than one, about -- the  
13 question was is this valuable to patients? And  
14 what I wrote was I think we got a lot of evidence  
15 that patients value being informed and involved.  
16 And that didn't say did patients think these are  
17 the right four questions? And I don't -- I did  
18 not ask -- I don't have data that -- or  
19 experience to where we asked patients whether  
20 they thought these were the right four questions.  
21 So, I guess the answer is no.

22 But I do think the issue about whether

1       that's the right role for patients to play is a  
2       little bit tricky because there's just so many  
3       different ways to go, the things you could ask  
4       people. And likely didn't ask them -- talk to  
5       them about their goals and concerns and that sort  
6       of thing, which might have sounded more like what  
7       they wanted to talk about. Anyway, the answer is  
8       I don't have experience with where patients voted  
9       on whether these were the right questions.

10               CO-CHAIR PARTRIDGE: Sherrie?

11               MEMBER KAPLAN: Thanks, Jack. To  
12       follow up on the content validity question, you  
13       didn't pull these out of the blue, though. These  
14       were -- you defined the domain of observables and  
15       you picked the -- just to follow up on Lisa's  
16       question, you saw a group of folks --

17               DR. FOWLER: Right, I think there's a  
18       pretty well-developed --

19               (Simultaneous speaking.)

20               MEMBER KAPLAN: -- validity  
21       estimation. Yes.

22               DR. FOWLER: -- structure of whether

1 the elements on shared decision ought to happen.

2 MEMBER KAPLAN: Right.

3 DR. FOWLER: And that's where these  
4 came from.

5 MEMBER KAPLAN: So those were --

6 (Simultaneous speaking.)

7 DR. FOWLER: Yes.

8 MEMBER KAPLAN: Okay. So my question  
9 is -- and this isn't meant to be a criticism.  
10 It's this is one of the few proposals, at least I  
11 reviewed, that actually looks at an effort to  
12 improve quality and the responsiveness of the  
13 measure to those efforts to improve quality. So  
14 in the shared decision making sites it looks like  
15 measures responsive to efforts to improve shared  
16 decision making.

17 So then my question is how did you  
18 randomize? Because if you randomize within site,  
19 it's a little bit different than if you randomize  
20 site. Did you do cluster -- how did you do that?

21 DR. FOWLER: Yes, I mean, I think  
22 interventions about changing clinical practice,



1       it's hard not to contaminate. One of the  
2       reasons, I think people like historical controls  
3       kind of better so that you can sort of see how  
4       are things going first and then introduce  
5       something and then see if you change things. But  
6       it's the same guys and gals who are doing it.

7               And that takes a variable out, because  
8       once you start -- once a clinician -- the notion  
9       that a clinician is going to share decisions with  
10      patient A and then not B, or even that within a  
11      practice that half the doctors are going to be  
12      doing shared decision making and using decision  
13      aids and the other half are not, I think that  
14      really gets hard to do. And we've fooled around  
15      with that, but I think we've always felt like we  
16      had to randomize practices.

17             MEMBER KAPLAN: So you randomized  
18      practices?

19             DR. FOWLER: Yes.

20             MEMBER KAPLAN: Okay.

21             CO-CHAIR PARTRIDGE: Nicole?

22             MEMBER FRIEDMAN: My question is about

1 is this focused specifically on the relationship  
2 in shared decision making between the provider  
3 and the patient, or does it also include  
4 providers that work in care teams, and how --  
5 yes.

6 DR. FOWLER: Yes, I think it includes  
7 anybody in. I'm not -- I think the future and  
8 getting this right is going to actually involve  
9 non-physicians in particular. And I think the  
10 wording is such that people -- and people do  
11 report if they have the conversations. It  
12 doesn't matter whether they had it with a health  
13 coach or a nurse or with a doctor. That all  
14 counts. And I think that's really an important  
15 part of shared decision making is expanding the  
16 team because it looks better.

17 MEMBER FRIEDMAN: And would there be  
18 an -- I'm sorry if this is more than use and  
19 usability. Is there training that would be  
20 developed and implemented to knowing if there's  
21 varying levels of comfort with having those  
22 conversations, especially if they go to health

1 coaches or non-licensed --

2 DR. FOWLER: Yes, there are a couple  
3 training programs that have been developed now  
4 that -- both for providers of all ilks about how  
5 to do this. And there are online ones that are  
6 now available, a couple of them. I think AHRQ  
7 has one.

8 MEMBER FRIEDMAN: And did the people  
9 that were surveyed, did those providers have the  
10 training?

11 DR. FOWLER: No, they didn't, because  
12 these people actually sort of were the pioneers  
13 of sorts. They did have a -- we did have a  
14 weekly, a monthly kind of support group phone  
15 call so that at least a lead person from each  
16 site -- I don't know if -- people talked about  
17 the problems they had and how they solved them  
18 and successes and things like that. So we kind  
19 of made it a working seminar, but we didn't have  
20 the formal training then. But now there is  
21 training available and it's starting to be used.

22 CO-CHAIR PARTRIDGE: I am sorry.

1 Peter?

2 MEMBER THOMAS: I have a very brief  
3 question and it really doesn't honestly bear on  
4 these questions that we're answering here, but  
5 I'm just curious. Have you ever asked the pool  
6 of people that did identify in the affirmative of  
7 being involved in the decision making and  
8 answering those questions that you laid out  
9 positively -- have you ever asked would your  
10 decision have been different had you not felt  
11 that you were fully informed or had that --

12 DR. FOWLER: Boy, that's a hard  
13 question. I think the answer is no. Certainly  
14 we haven't done it in a structured way.

15 MEMBER THOMAS: You see what I'm  
16 getting at? I'm trying to figure out whether the  
17 process is going to --

18 (Simultaneous speaking.)

19 DR. FOWLER: Oh, we have anecdotes all  
20 over the place of people saying, oh, gosh. I  
21 mean, but we definitely have gotten feedback from  
22 patients who'd see decision aids, talk to their

1 doctors and say, oh, my gosh, I didn't understand  
2 that or -- either because -- I mean, because they  
3 said, oh, gosh, if I -- now that I know that a  
4 herniated discs get better on their own in a year  
5 or two if I don't have surgery, why would I want  
6 to do that? Or now that I know PCI is not going  
7 to save my life and I don't have any symptoms,  
8 why would I want to have that?

9 I mean, we definitely -- there is the  
10 a-ha moments and it's separating the information  
11 from the conversation with the doctor, I can't  
12 quite do that.

13 MEMBER THOMAS: Right.

14 DR. FOWLER: But shared decision  
15 making, absolutely. All of -- the average of  
16 tons of -- not tons, dozens of randomized trials  
17 with patients who see decision aids and don't  
18 show that they're more conservative about  
19 interventions. That is, you get less -- patients  
20 opt for less intervention when they're informed  
21 in the U.S. and then under usual care. And that  
22 I think has been pretty well -- about 25 percent

1 less fewer. Though probably depends on the mix  
2 of interventions that you're studying, but that's  
3 the average across let's say several dozen  
4 studies like that. So there's no doubt that  
5 being informed and involved has an impact on  
6 decisions on average.

7 And it tends to be in this country --  
8 in the U.K. you get a few things that go up  
9 higher because their rates of some interventions  
10 are lower, but they're more conservative. But in  
11 the U.S. it's almost all due to have less  
12 intervention. No, not for everybody, obviously.  
13 It goes both ways.

14 CO-CHAIR PARTRIDGE: Okay. We ready  
15 to vote on validity?

16 Desi?

17 MS. QUINNONEZ: Voting is now open for  
18 the validity of Measure 2962 including  
19 specifications consistent with evidence, testing,  
20 threats addressed, exclusions, risk adjustment  
21 stratification, meaningful differences,  
22 comparability, multiple specifications and

1 missing data.

2 Option No. 1 is high; option No. 2,  
3 moderate; option No. 3, low; and option no. 4,  
4 insufficient.

5 (Voting.)

6 MS. QUINNONEZ: Waiting for one vote.

7 (Pause.)

8 MS. QUINNONEZ: Can we have your  
9 submit your votes one more time just to make sure  
10 everyone -- all votes went through?

11 (Voting.)

12 MS. QUINNONEZ: All votes are in.  
13 Thank you. Voting is now closed. The results  
14 are 11 percent voted high; 79 percent voted  
15 moderate; 11 percent voted low; and 0 percent for  
16 insufficient.

17 CO-CHAIR PARTRIDGE: Okay. Moving on  
18 to feasibility. Comments? Sam?

19 MEMBER BIERNER: I want to ask, there  
20 was a question that was raised in the comments  
21 about what are the -- are you going to have any  
22 public reporting of this, or how is it -- other

1       than being used at a hospital level or some other  
2       group level, is there any plans to have any  
3       public reporting of this information or use it  
4       more widespread?

5               DR. FOWLER:  Yes, I mean, that's not  
6       a role we can play actually, so I don't have any  
7       particular plans.  I think there are a lot of  
8       contexts in which people are thinking about --  
9       they want to measure whether or not shared  
10      decision making is happening.  And I think this  
11      is a reasonable way to do it.  So that will vary  
12      by the context in which people want to use it, I  
13      guess is the right answer.  I think it certainly  
14      could be publically reported, but that's not  
15      something that we can have a direct role in.

16             CO-CHAIR PARTRIDGE:  Peter?

17             MEMBER THOMAS:  So a similar comment  
18      to the one I made yesterday.  When you're talking  
19      about mailing surveys and then following up with  
20      phone calls, that's kind of time-intensive and  
21      maybe -- I don't know expense.  The data wasn't  
22      submitted for how much, how much expensive that



1 is to do. But are there ways to take advantage  
2 of IT and other ways to gather this data, or is  
3 this just a different population?

4 DR. FOWLER: Yes, everybody wants to  
5 do that, and I think that's where we're going to  
6 be in the future. The response rate experience  
7 has been very -- quite variable there. I know of  
8 one place -- I think places that have some kind  
9 of savvy client populations that are kind of  
10 comfortable with their portals and do better --  
11 and the ideal way to do this would be after a  
12 visit to have questions -- a letter go out and to  
13 get the patient to go to a portal or something,  
14 click on a URL and answer the questions there.  
15 And I think that will be the future probably for  
16 a lot of people.

17 But at the moment, as I say, the  
18 response rates have been much worse with that  
19 approach than they have been in -- in most  
20 settings though -- so if you were in a setting  
21 where you have a population that will work with  
22 that, I think that's fine. And we certainly

1 collected these data online, so the questions  
2 worked just fine there. So it's really just a  
3 matter of feasibility and what a place can  
4 accomplish. But the one I don't think you should  
5 do is to have a nurse collect the questionnaires  
6 in the offices, because we actually have data  
7 that show that that really gets pretty distorted  
8 results.

9 But they're not huge samples that  
10 you're going to have -- that a place would have  
11 to do. And I wouldn't think you'd just do this  
12 continuously. In fact, I think you might even  
13 vary the topic from year to year. You might do  
14 hips one year and backs another year. So it  
15 might not be an astounding thing, but somebody --  
16 if you do it by mail, somebody's got to do the  
17 work and have follow-up phone calls, and that  
18 does take some time from somebody, either from a  
19 practice or somebody they hire.

20 CO-CHAIR PARTRIDGE: Becky? Sorry.

21 MEMBER BRADLEY: Thank you. I guess  
22 I'm still struggling with the lack of information

1 from patients who chose not to have surgery. And  
2 you've explained why those were not included  
3 here, but how does this relate to or overlap with  
4 CAHPS surveys and how are these questions  
5 different? Because if they were used in a CAHPS  
6 environment, then you would have data from people  
7 who chose one method over the other. So is there  
8 any discussion on harmonizing these?

9 And the other issue with that is we're  
10 hearing from patients that they're being surveyed  
11 repeatedly once they got home and they're kind of  
12 getting the surveys confused as to which  
13 environment they're being surveyed about again.  
14 So I was just wondering if that's been a  
15 discussion with your --

16 DR. FOWLER: Yes, well, obviously  
17 CAHPS is a survey that happens. And actually  
18 they have -- the patient-centered medical home  
19 instrument had some questions that were taken  
20 from -- were derived from this a bit. But the  
21 problem that they have in -- that you have in  
22 CAHPS is that the rates -- given the sample

1 sizes, the rates at which any particular decision  
2 is made are so low that you don't get adequate  
3 samples.

4 Because if you sample even 300 visits  
5 from something, the rates at which you'll find  
6 anybody who made any of these kinds of decisions,  
7 you might pick up -- I mean, they couldn't even  
8 do specifics. They were asking about medication  
9 decisions, but they had to lump all the  
10 medications together. And the problem with that  
11 is that if you're summarizing across several  
12 decisions, the data become mush. The people just  
13 -- we really know you've got to ask about one  
14 decision at a time to get variance.

15 And so, I think the problem is you  
16 just can't get adequate samples that way. I  
17 mean, that is the way we got samples of people  
18 who didn't make the decisions is to have a really  
19 big sample of 40-year-olds. And for that you get  
20 a lot of people who talked about knee surgery or  
21 talked about statins who didn't make the  
22 decisions. I could not agree more that I want to

1 know how those people are treated, too, but I  
2 don't know how to make it feasible to compare  
3 practices.

4 And if you think the burden -- well,  
5 the burden will be whatever it is for targeting  
6 people who have particular -- these  
7 interventions, but if you tried to make the  
8 samples big enough to find even this very small  
9 number of decisions that will happen often enough  
10 to justify a -- to get a reliable result on  
11 decision making, it will just be huge. So it's a  
12 practicality problem at the moment.

13 CO-CHAIR PARTRIDGE: Further comments?  
14 If not, I think we're ready to vote on  
15 feasibility.

16 Desi?

17 MS. QUINNONEZ: Voting is now open for  
18 feasibility of Measure 2962, including data  
19 generated during care, electronic sources and  
20 data collection can be implemented. Voting  
21 options are 1, high; option No. 2, moderate;  
22 option No. 3, low; and option No. 4,

1 insufficient.

2 (Voting.)

3 MS. QUINNONEZ: Okay. All votes are  
4 in and voting is now closed. The results are 0  
5 percent voted high; 63 percent voted moderate; 37  
6 percent voted low; and 0 percent voted for  
7 insufficient.

8 CO-CHAIR PARTRIDGE: Moving on to  
9 usability. Discussion? Sherrie?

10 MEMBER KAPLAN: Jack, how do you see  
11 this being used?

12 DR. FOWLER: Well, I think the people  
13 who are thinking about -- I don't -- I mean, one  
14 obvious place that I think may get -- generate a  
15 need is in the accountable care organization  
16 evaluations, that somebody is going to have to  
17 decide whether shared decision making is  
18 happening.

19 And I think in that context the notion  
20 of -- I think I could see picking a procedure of  
21 the year or something and having -- today we're  
22 going to take a look at how PCI decisions are

1       being made in samples. And so, we're going to go  
2       make people -- get surveys back from 100 people  
3       who had PCIs and we're going to find out how the  
4       decision making process went. Ideally, you'd  
5       also get questions about whether they understood  
6       what was it was about, too. So that's one kind  
7       of thing.

8                       And because I -- a lot of people are  
9       talking more and more that shared decision making  
10      use is your standard. I don't know all the  
11      places that are happening -- there's all -- but  
12      -- and what the potential ways of evaluating are  
13      going to be, but I know we need some questions to  
14      ask if that's going to be important. And I think  
15      these are the best that I know about at the  
16      moment. And I hope we'll keep learning more  
17      about them and I hope maybe we'll even make them  
18      better then --

19                   MEMBER KAPLAN: So it's mostly for  
20      quality improvement, you're saying?

21                   DR. FOWLER: Well, in this context I  
22      think it's quality improvement. It's also needed

1 for research all the time when we're trying to  
2 figure out how to stimulate better interactions  
3 between patients and providers and more shared  
4 decision making. And I think this is an obvious  
5 measure for researchers to use on a -- and I  
6 think if NQF says that this is an okay way to do  
7 it, I think that would increase the odds that  
8 they'll use this approach, and that would  
9 probably be better. I think that's my --

10 CO-CHAIR PARTRIDGE: Sherrie, I'm just  
11 going to comment here. I live in a state, New  
12 York, which is enamored of the concept of value-  
13 based purchasing. This issue lends itself to  
14 that arena because it's entirely possible you'll  
15 see disparities, as Dr. Fowler has noted, and  
16 those of us who love Dartmouth Atlas know, you  
17 can find communities where the incidence of say  
18 hip surgery is much greater than it is in  
19 another.

20 And it will certainly be very  
21 appealing to somebody crafting a QI program in an  
22 ACO or in a clinic to say, oh, here's a measure



1       that can begin to help us understand what's going  
2       on. And I frankly -- I have a feeling this may  
3       be quite popular.

4               MEMBER KAPLAN: You are not going to  
5       get a pushback from me on this issue. On another  
6       hand, I was just interested to see the vision of  
7       the measure developer here and whether this was  
8       ultimately going to land in the accountability  
9       zone. And if so, obviously we're going to need  
10      more data and much more information about how  
11      this works in that space rather than quality  
12      improvement. But if it right now is being  
13      considered as a quality improvement measure, it  
14      helps us, I think -- or it helps me at least to  
15      understand what the use and usability issue is.

16             CO-CHAIR PARTRIDGE: Are we ready to  
17      vote on usability?

18             MS. QUINNONEZ: Voting is now open for  
19      usability and use of Measure 2962, including  
20      accountability, transparency, improvement,  
21      progress demonstrated, benefits outweigh evidence  
22      of unintended negative consequences.

1                   Option No. 1 is high; option No. 2,  
2                   moderate; option No. 3, low; and option No. 4,  
3                   insufficient information.

4                   (Voting.)

5                   MS. QUINNONEZ: All votes are in and  
6                   voting is now closed. The results are 32 percent  
7                   voted high; 58 percent voted moderate; 11 percent  
8                   voted low; and 0 percent voted for insufficient  
9                   information.

10                  CO-CHAIR PARTRIDGE: Last question:  
11                  Overall, do we recommend this measure for  
12                  endorsement by NQF?

13                  Desi?

14                  MS. QUINNONEZ: Voting is now open for  
15                  the overall suitability for recommendation for  
16                  endorsement of Measure 2962. Option No. 1 is  
17                  yes; option No. 2 is no.

18                  (Voting.)

19                  MS. QUINNONEZ: Looking for one more  
20                  vote.

21                  All votes are in. Voting is closed.  
22                  The results are 100 percent voted yes; 0 percent

1 voted for no.

2 CO-CHAIR PARTRIDGE: Dr. Fowler, this  
3 Committee doesn't do that very often.

4 DR. FOWLER: Well, I definitely want  
5 to thank the Committee, both for your thoughtful  
6 comments -- and I also say that I'm dazzled by  
7 the amount of material that you all have to read  
8 in order to do your jobs. And I think it's very  
9 outstanding and you should be well-thanked for  
10 your service.

11 CO-CHAIR STILLE: Well have a five-  
12 minute bio and coffee break.

13 (Whereupon, the above-entitled matter  
14 went off the record at 9:59 a.m. and resumed at  
15 10:07 a.m.)

16 CO-CHAIR STILLE: Great. Welcome  
17 back. We're going to proceed with the discussion  
18 of measure 2958 which is Informed, Patient  
19 Centered Hip and Knee Replacement Surgery Measure  
20 from Mass General Hospital in Boston. We have a  
21 measure developer here to talk to us. The  
22 discussants, primary discussants, will be Sherrie

1 Kaplan, Stephen Hoy, and Rebecca Bradley. And we  
2 are ready to go. So take it away.

3 DR. SEPUCHA: So good morning. My  
4 name is Karen Sepucha and I run the Health  
5 Decisions Science Center at Mass General  
6 Hospital. So I'm here to present Measure 2958,  
7 which is informed, patient centered hip and knee  
8 replacement surgery. And I think this is very  
9 complementary to the discussion we just had  
10 around shared decision making measure.

11 The whole purpose of shared decision  
12 making and the goal of shared decision making is  
13 really to ensure that patients are well informed  
14 and they're getting treatments that match their  
15 preferences. And so what this measure does is  
16 look at that and provide a way to assess that for  
17 folks making elective surgery decisions.

18 These are high-stakes decisions. Hip  
19 and knee replacement is a very common decision.  
20 And although there are appropriateness criteria  
21 to determine whether or not someone is clinically  
22 eligible for it, just because someone is

1 clinically eligible for one of these procedures  
2 doesn't mean they should have it. Someone really  
3 should only have one of these surgeries if they  
4 are well informed and have a clear preference for  
5 it.

6 So what the measure does is try to  
7 evaluate the quality of those decisions and it is  
8 based, the performance measure is derived from  
9 survey instrument, a decision quality survey  
10 instrument that we have developed and used in  
11 several different arenas.

12 There are six items to the survey,  
13 five knowledge questions, and then one item is a  
14 preference, elicits patient's preference. This  
15 is the kind of information that really can only  
16 be ascertained from patients themselves. It is  
17 not routinely documented in a chart or anywhere  
18 else, so we really do need to be asking patients  
19 about this in order to understand.

20 And the evidence in the submission  
21 does provide some evidence around gaps in the  
22 measure. The studies that we have done have

1 found that there are maybe about a third to a  
2 half of the sites that we were surveying could  
3 actually meet the criteria, so patients who  
4 actually were both well informed and received  
5 care that was consistent with their goals.

6 And then, there was also evidence that  
7 suggested ways to improve that, so sites that had  
8 used patient decision aids, who were engaged in  
9 more shared decision making had higher rates of  
10 this.

11 So we've developed these decision  
12 quality instruments, the surveys upon which this  
13 measure is based for several different  
14 conditions, about 14 different topics. This is  
15 the first performance measure that we're  
16 proposing, so this is new. This is new for us  
17 and I think as some of the comments noted,  
18 there's limited data so far that we have, but we  
19 are interested in increasing the amount of data  
20 to better understand how this performs, as well  
21 as potentially extending it to many other  
22 different topics.

1           I do think it complements the measure  
2   that Jack just proposed around shared decision  
3   making, which is sort of a general process  
4   measure, so what was the conversation? And this  
5   really complements it to say well, okay, we could  
6   have a good conversation, but did patients  
7   actually understand the information? Did they  
8   have a clear preference for this procedure? And  
9   those are things that we really want to know  
10   before we move forward with claiming that they  
11   had a good quality decision. So I think I'll  
12   stop there and I'm happy to take obviously  
13   questions.

14           CO-CHAIR STILLE: Great. Thanks.  
15   We'll open the discussion. Sherrie, Stephen, or  
16   Rebecca would like to start?

17           MEMBER KAPLAN: We have a problem in  
18   decision making.

19           CO-CHAIR STILLE: You're sharing the  
20   decision to talk at the same time.

21           MEMBER KAPLAN: Okay, so thank you for  
22   that presentation. I have a couple of questions

1 because this is a new measure and I was looking  
2 closely at the questions themselves. And some of  
3 them I note like after knee replacement, how many  
4 months does it take most people to get back to  
5 doing their usual activities? And things like  
6 the baseline state would make that a little bit  
7 interesting to try and interpret from a patient's  
8 standpoint.

9 If 100 people have knee replacement,  
10 how many will have a serious complication within  
11 3 months after surgery related to the surgery?  
12 So there are some questions I have about question  
13 content. But then I also was looking at sort of  
14 the -- well, I'll come back to risk adjustment  
15 and the Woloshin numeracy and risk literacy kind  
16 of issues in just a second.

17 So this is a new measure and so the  
18 data, as you aptly pointed out, are somewhat  
19 limited. The reliability data that you provide  
20 are on sort of the test/retest reliability, for  
21 example, and the time interval there was like --  
22 I forget what it was, four weeks? Four weeks,



1       yes. And so that looked good.

2               The practice level though, if this is  
3       meant to be a practice level variable used at the  
4       practice level, what you would want is between  
5       versus within practice variation, not a split  
6       half reliability. And that may be an issue of  
7       the guidance you got from NQF. But that wouldn't  
8       be what we would ultimately be looking for if  
9       this is intended to be used at the practice  
10      level.

11              So my first question is is that the  
12      ultimate intent for this? And if so, where in  
13      the process are you with respect to estimating  
14      how good this is for practice level  
15      discrimination?

16              DR. SEPUCHA: So I think there is some  
17      flexibility, but do you mean provider level  
18      versus practice level?

19              MEMBER KAPLAN: No, patient level  
20      versus practice level.

21              DR. SEPUCHA: Patient level versus  
22      practice level. And I also did get some comments

1 back from my statistician as well that might have  
2 some additional information on what the test was  
3 that she ran and what we were looking at. And  
4 we're also sort of limited by the sample size in  
5 terms of what we could say about different  
6 practice level things.

7 So I think ideally we would want to  
8 have it at the practice level, as well as at an  
9 individual level. As Jack was mentioning, a lot  
10 of the shared decision making does kind of go on  
11 at a practice level whether it's do you have  
12 access to decision aids? Do you have nurse  
13 practitioner helping with education? So these  
14 could reasonably be assessed at a practice level  
15 to see whether or not they're doing things well.

16 MEMBER KAPLAN: I keep going, Chris?

17 CO-CHAIR STILLE: Yes, absolutely.

18 Keep going.

19 MEMBER KAPLAN: Okay, so a couple more  
20 things. Discriminant validity in terms of  
21 patients whose providers had the decision aids  
22 versus folks who didn't looked very positive and

1 in that sense it's like responsive to an effort  
2 to improve quality in this area. But then I also  
3 noticed that it looked like, and correct me if  
4 I'm wrong, it looked like you were comparing the  
5 provider's knowledge to the patient's knowledge  
6 for evidence of discriminant validity.

7 And my question would be did you not  
8 or could you not have compared people with high  
9 numeracy to low numeracy on whether or not they  
10 got fairly good scores or not so good scores?  
11 Why choose groups that were going to be pretty  
12 much that far apart on this issue?

13 DR. SEPUCHA: So we did set up a  
14 couple of different measures or tests for  
15 discriminant validity. So one was a group who  
16 got a decision aid and a group who didn't, so  
17 those were sort of patient level and compared  
18 those and we found some significant differences  
19 on the knowledge questions.

20 The other, just because a lot of  
21 places weren't using decision aids, so we set up  
22 -- you know, we had healthy volunteers, so people

1 who didn't have the condition versus patients  
2 with the condition versus providers. And part of  
3 that, obviously we expected a pretty big  
4 difference between providers and the patients.  
5 But we were also doing that in a sense to look at  
6 the content validity of the items. So if  
7 providers were getting the questions wrong, then  
8 there's probably something wrong with the  
9 question in terms of -- or it was either  
10 controversial or -- you know, we also wanted to  
11 make sure that actually these questions had,  
12 quote, a pretty clear answer that people could  
13 consider correct.

14 MEMBER KAPLAN: How many of the  
15 doctors got it wrong?

16 DR. SEPUCHA: So, it actually depended  
17 -- we did a multi-disciplinary group of doctors.  
18 The surgeons actually, for this one, the surgeons  
19 and the specialists pretty much got them all  
20 right. Primary care doctors it was a little bit  
21 different though. And so that was interesting.  
22 And we did this across -- we've done this across

1 many different topics. I think the biggest one  
2 was NDC. The primary care docs had a very --  
3 their knowledge was not as good as we would like  
4 it to be.

5 MEMBER KAPLAN: Thank you. One final  
6 question. The other thing is this measure is  
7 administered two years, up to two years after the  
8 procedure? Is that accurate?

9 DR. SEPUCHA: So we've done it in  
10 different ways, depending on the study and the  
11 proposal here, I think, is similar to what Jack  
12 was wrestling with is figuring out how do we  
13 reliably find a sample of patients? And so we  
14 can reliably find a sample of patients who have  
15 had the surgery and then the studies that we have  
16 done have looked up to two years after and  
17 surveyed patients and so we have a good data set  
18 there.

19 In our own institution, we've actually  
20 been surveying patients the week after their  
21 visit with the surgeon, but we can find them a  
22 lot easier and we're screening them and I have a

1 full-time research coordinator. So ideally,  
2 there are potentially other ways to do this at  
3 different time points, but for now, that was the  
4 one that we thought was the most feasible.

5 MEMBER KAPLAN: Right, because the  
6 questions of somewhere down the way, decisional  
7 regret and things like that get swept into line  
8 with how well you've done and you would worry  
9 about cognitive dissonance for people who had  
10 done very well and they're still upset about the  
11 decision they made. Those intervals take -- as  
12 I'm assuming as you developed this further, you  
13 will help us with the specifications on exactly  
14 where you're looking for the magic interval to  
15 administer this or say forget it, game over. We  
16 can't do this.

17 DR. SEPUCHA: Yes.

18 CO-CHAIR STILLE: Okay, Becky.

19 MEMBER BRADLEY: I agree with  
20 everything Sherrie said, but also had some  
21 questions about the survey itself and how these  
22 questions were derived. They're very different

1 from other types of questions and I'm assuming  
2 this survey, it made more sense after hearing the  
3 first presentation, but are you anticipating that  
4 you would also ask that set of questions?

5 Because there's some relationship to these two  
6 studies. So would this be the decision aid  
7 survey that would be used to support the previous  
8 study? I'm not clear as to how they interrelate.

9 DR. SEPUCHA: So, you know, really  
10 early in Jack's comments he sort of had this idea  
11 or proposed this sort of conception of how we do  
12 measure the quality of the decision for these  
13 areas and so the idea that you want to make sure  
14 someone is meaningfully involved in the decision-  
15 making process and that was Jack's measure. And  
16 that's a little more generic.

17 We can have the questions kind of  
18 generically go across the different topics. But  
19 the other two pieces are you need to have  
20 somebody who is well informed. So they have to  
21 understand the key facts. And we've done a lot  
22 of surveys trying to ask patients how informed do

1       they feel? Did they think they understood the  
2       benefits and harms in a generic way?

3               And what we found in that decision  
4       study, there was zero correlation between their  
5       perceptions of feeling informed and their ability  
6       to answer knowledge questions. So we sort of  
7       moved forward with saying you know what, in order  
8       to actually figure out if someone is informed, we  
9       need to ask them knowledge questions. We need to  
10      actually figure out what are the key facts that  
11      someone reasonably should know who is making this  
12      kind of a decision.

13              For here, it does focus sort of more  
14      on the surgical benefits, harms, what's the  
15      likely recovery time. Those are the issues that  
16      were really important to patients when we were  
17      trying to figure out what kind of information do  
18      you wish you had known or what information do you  
19      think is really important for people making this  
20      decision to understand. And so, you know,  
21      informed, involved, and then receiving treatments  
22      that match their preferences.



1                   And so in this measure, it's just a  
2                   simple one item which is which treatment did you  
3                   prefer? Did you prefer to have surgery, non-  
4                   surgical options, or were you not sure? And we  
5                   think that the standard for someone who is  
6                   actually going to have surgery, they should have  
7                   a clear preference for it. And if you don't,  
8                   then we shouldn't be operating on them. They  
9                   should be able to state that. And so that's  
10                  where this one came up. So these are sort of the  
11                  decisions-specific items that really have to be  
12                  tied to a specific topic. And that's why we kind  
13                  of separated the two different measures, but we  
14                  often use them together in the same survey.

15                 MEMBER BRADLEY: So patients' input  
16                  was solicited in the development of the  
17                  questions?

18                 DR. SEPUCHA: Mm-hmm.

19                 MEMBER BRADLEY: And these were the  
20                  questions the patient groups said were important  
21                  to them in terms of knowledge?

22                 DR. SEPUCHA: Mm-hmm.

1                   MEMBER BRADLEY: I guess the  
2                   exclusions were kind of interesting. So if they  
3                   failed, three years after surgery, up to three  
4                   years after surgery, if you couldn't remember a  
5                   specific statistic about -- I was curious. I  
6                   probably couldn't remember myself. But it seems  
7                   like you excluded a lot of people from the study  
8                   based on the knowledge. But the lack of  
9                   knowledge -- if they failed the knowledge  
10                  question, then they weren't included in the  
11                  study? Is that the way I heard --

12                 DR. SEPUCHA: So do you mean like  
13                 excluded from the sample, or they just -- so we  
14                 set a criteria, a threshold, so there's five  
15                 knowledge questions. And so we set in our  
16                 threshold you have to have a passing score. So  
17                 you have to get three or more correct answers to  
18                 be counted as meeting our criteria for being  
19                 informed. So I'm not sure, technically, that's  
20                 not excluding people who didn't --

21                 MEMBER BRADLEY: Okay.

22                 DR. SEPUCHA: -- but it's not counting

1       them as being well informed.

2               MEMBER BRADLEY:   So, but were they  
3       tested at the time that they made the decision  
4       for surgery as being well informed or was it only  
5       tested at --

6               DR. SEPUCHA:   So we surveyed them up  
7       to two years after the surgery in the samples  
8       here.

9               MEMBER BRADLEY:   Okay.

10              DR. SEPUCHA:   But I think it gets  
11       back to the issue that we were talking about  
12       earlier about the timing.

13              MEMBER BRADLEY:   Okay.   Thank you.

14              CO-CHAIR STILLE:   Stephen and then  
15       Lisa.

16              MEMBER HOY:   Yes, just to highlight,  
17       they're not excluded.   They're identified as not  
18       knowledgeable about their decision.   To get  
19       excluded, you have to not identify surgery as  
20       your preference.   So they're just looking at --  
21       right, they're just looking at people who  
22       preferred surgery and were they -- and to

1 highlight the difference between this one and the  
2 last one, they're looking at their actual  
3 knowledge of those decision criterias as  
4 identified decision criterias for patients to  
5 preferred surgery compared to their process of  
6 engagement. So this is a little more direct.

7 And I have a question, but I'm going  
8 to have to come back to it when I remember it.

9 CO-CHAIR STILLE: Why don't I let Lisa  
10 go and then you can remember.

11 MEMBER SUTER: Again, this is my  
12 second disclosure. So I'm involved in the  
13 development of a patient reported outcome measure  
14 for hip and knee patients undergoing elective  
15 procedures. It's not related to this. We're  
16 looking at pre- and post-pain and function  
17 assessments, but just disclosures.

18 A couple questions, so first of all,  
19 have you -- were surgeons involved in the  
20 development of the questions? One of the things  
21 I hear working with a technical expert panel and  
22 other orthopedic surgeons in the community is the

1 distinction between hip and knee replacement  
2 recovery. And that patients -- and I'm also a  
3 rheumatologist -- patients recovering from hip  
4 surgery actually are far more functional more  
5 rapidly. And so I'm surprised to see the time  
6 frame for recovery for both of those surgeries is  
7 identical. Because when you speak to surgeons  
8 and they speak to their patients, they highlight  
9 the difference that if you've been through a hip  
10 replacement, you're going to expect a different  
11 trajectory from the knee replacement.

12 So one question is how were clinical  
13 experts involved in the development of this and  
14 the testing of this? 2) reiterating what people  
15 have already said, I think if you're going to  
16 make this a meaningful measure, you have to bound  
17 the time frame that you're collecting this  
18 information because two years is, one, it  
19 questions what the relevance to clinical care for  
20 that particular patient and provider are.

21 And I guess the last is just thinking  
22 about exclusion. I saw you are looking at

1 primary surgeries. What about non-elective  
2 surgeries? And are you -- have you considered  
3 excluding patients who are -- or at least  
4 handling them differently? I know you're not  
5 risk adjusting, but a patient who comes in for a  
6 fracture, it may be completely unrealistic to  
7 expect that person to have any of the criteria  
8 for meeting an IPC score in your tool.

9 DR. SEPUCHA: So the first one, so in  
10 terms of the development of the items, we had  
11 significant involvement from patients as well as  
12 providers. And so the providers spanned from  
13 surgeons to primary care docs to physical  
14 therapists and nurses. So we had a multi-  
15 disciplinary group of providers.

16 In addition, we also actually have  
17 sort of annotated answers to the knowledge  
18 questions with relevant citations, so the idea is  
19 that these are evidence-based. You did pick up  
20 on the one where the evidence is the squishiest,  
21 which recovery time in trying to get general ball  
22 parks for recovery time that makes sense.

1           So the idea is not sort of precision  
2     with these, with any of the questions, that they  
3     know that it's 84 versus 85, it's really  
4     generally like do they understand it's a couple  
5     of months rather than year or two weeks. Do they  
6     understand at least generally? So that's what  
7     we've tried to do.

8           It's definitely a balance. But we  
9     have our clinicians sort of review it and the  
10    knowledge questions get reviewed every two years  
11    just to make sure that nothing is changed such  
12    that the knowledge questions would need to change  
13    to either be updated or to make sure that they're  
14    accurate. So that's the involvement in the  
15    knowledge questions.

16           Bounding the time frame, I do think  
17    that's a challenge with the sampling. And I  
18    agree. Ideally, we would want to be doing this  
19    closer to the -- even before the decision, the  
20    surgery was carried out. We've been doing  
21    different things. My other hat at MGH, I  
22    actually integrate, responsible for integrating

1 shared decision making across the hospital. So  
2 we've been working with our orthopedic  
3 departments to actually put this as part of their  
4 registry. They're already assessing patient-  
5 reported outcomes for folks going for hip and  
6 knee replacement and adding six questions. It's  
7 very reasonable for them to do. They always get  
8 a pre-op assessment. So that's the eye toward  
9 the future of where we would want to go is to  
10 figure out can this get integrated into -- and  
11 one of the reasons we picked hip and knee because  
12 that's part of the almost eligibility criteria is  
13 you have to have a WOMAC score or a patient-  
14 reported outcome score of a certain level. And  
15 so we thought that this might be a way to  
16 integrate that. We just don't have any data on  
17 that yet. But that would be the ideal.

18 For the non-elected surgery, I think  
19 we'll probably have to look into it, whether we  
20 could actually refine the code so that we could  
21 try and remove those. I'm not sure how many  
22 primary or hip or knee replacements are non-



1 elective. But that's good. We'll look into  
2 that.

3 CO-CHAIR STILLE: Great. Stephen and  
4 Lee and Linda.

5 MEMBER HOY: Just on that non-elective  
6 part, I would still argue that the patient should  
7 be informed about what their expectations of  
8 recovery and such, so I'm less worried about  
9 that.

10 My question was why the two years? I  
11 think you kind of mostly covered that, but it  
12 would be nice to see this kind of thing happen  
13 before. A good doctor is not somebody who just  
14 asks do you understand, it's show me how well you  
15 understand. So it would be nice to see it up  
16 front and so from what I understand though, it's  
17 a sampling issue and a data issue just to get  
18 your feet on the ground. But it seems like you  
19 answered my question. Thanks.

20 CO-CHAIR PARTRIDGE: Thank you. I'm  
21 going to pick up a little bit on some of the  
22 things that Sherrie said, raised. One really

1 goes to the two-year period. And I understand  
2 why you did it, but it seems to me that it  
3 probably renders this a little less useful.

4 If you have had the surgery and you're  
5 asked three or four or five months later what you  
6 knew, it's entirely possible that some of what  
7 you know you learned after you had the surgery.  
8 It might be particularly true in the case of  
9 someone for whom it didn't turn out quite as  
10 happily as they had thought. At that point, they  
11 start chatting with others and they start reading  
12 and they discovered oh, yes, well, I should have  
13 known. So they would answer this question  
14 correctly three months out, but they wouldn't  
15 have answered it correctly just before they  
16 actually made the decision.

17 The second is and I have to tell you  
18 I tested this on a sample of one. My husband has  
19 had both hips replaced. And he said you know, I  
20 would get some of these wrong. And yet, I would  
21 get them wrong even after my second surgery  
22 because I'm not really sure less than two months

1 or two months to six months which is right.

2 I don't know that you should flunk my  
3 doc because I'm missed less than two months or  
4 two to six months. I really knew a lot  
5 particularly by the time I had the second.

6 So his reaction was that perhaps it  
7 wasn't quite equitable, again, with number four.  
8 If 100, how many will have less hip pain after  
9 the surgery, 30, 50? I just have to volunteer.

10 CO-CHAIR STILLE: Okay, Linda.

11 MEMBER MELILLO: So I'm going to beat  
12 the dead horse. My concern was also with the  
13 exclusion and just that even if somebody knew  
14 that at three or four months post-surgery, by two  
15 years, they've moved on and I would say that even  
16 somebody who had a wonderful memory would have a  
17 difficult time recalling those kinds of detail so  
18 far out. So I'm just wondering if you did any  
19 time studies to see at what point people start  
20 becoming excluded or also developing the best  
21 time frame for which this should be administered.

22 DR. SEPUCHA: So I think the first

1        thing, I don't think anybody is excluded. I  
2        think the exclusion is maybe the wrong word. So  
3        they're not excluded. And yes, I agree, I would  
4        rather have the knowledge assessed earlier. So  
5        we do have data. I don't have it analyzed for  
6        today, but we have data from breast cancer where  
7        we had surveyed patients right after their  
8        surgery and then a year later. And if we're  
9        looking at the site level, so we had four  
10       different sites, the average knowledge score at  
11       the site level was the same which was surprising.  
12       We had actually predicted it would drop. That  
13       did mask -- there were some changes on the  
14       individual level. Some patients gained knowledge  
15       and some patients went from I had an answer to  
16       not sure. So we actually didn't find a very big  
17       difference up to a year later.

18                I think we need to do some more work  
19        to figure out what the deal is with the surgery  
20        for hip and knee. And we have a sample now that  
21        was surveyed a week after their visit and again  
22        six months after their surgery. So it's not two

1 years and I don't think we'd advocate two years.  
2 It was just some sites might need a little extra  
3 time to get that number of surveys in.

4 So I think we can look into getting  
5 better data on that and what kind of --  
6 empirically, what impact does that have. I think  
7 as we all recognize, you're not going to keep  
8 this information forever, but the gist of these  
9 answers, is that enough that's going to stick  
10 with you? Like, yes, most people actually do  
11 better after the surgery. There's very few side  
12 effects, but there are some -- but it's not zero.  
13 It takes a couple of months to recover. So those  
14 kinds of messages, we want to make sure people  
15 kind of keep --

16 CO-CHAIR STILLE: Okay, Sherrie, and  
17 then I think we need to start to move to a vote  
18 pretty soon.

19 MEMBER KAPLAN: I guess my question --  
20 I have one comment. And that is the timeliness  
21 of these things. Ideally, you'd like to find  
22 people just about the time they're making the

1 decision, right? You know, yes, and that's  
2 virtually impossible unless we change our data  
3 collection methods dramatically.

4           Then the question becomes timeliness.  
5 At what point, if on average your practice  
6 doesn't have very well informed patients, does it  
7 really matter if you've actually informed them  
8 post hoc or before the surgery? It should  
9 because you want to have them informed. On the  
10 other hand, if you're doing more shared decision  
11 making ultimately and you have better-informed  
12 patients, then the attribution to the practice of  
13 better shared decision making is -- I don't know  
14 what that does to you, but that's -- my instant  
15 reaction is there's kind of a couple of levels  
16 going on here. But before you answer -- address  
17 that, you've chosen not to risk adjust and  
18 because the Woloshin and this guy named  
19 Gigerenzer have issues about numeracy and risk  
20 literacy and how crummy that is in the  
21 population, even for very well educated people,  
22 some of whom are providers, as you found out,

1 have you -- did you consider gist versus numbers?  
2 Because Gigerenzer, et al. do that gist thing. I  
3 get the general gist of it, but I may get the  
4 numbers wrong. Did you weigh the sort of  
5 principle I get it that lots of people, not so  
6 many people versus actual numbers of people?

7 DR. SEPUCHA: So we tried to do both,  
8 actually. So one of the questions is who is  
9 likely to have less pain, people who have  
10 surgery, people who have non-surgical options or  
11 are they about the same? So that's sort of a  
12 gist kind of a question.

13 But then we also felt actually you  
14 need to have a bit of a realistic expectation  
15 about what the surgery is going to do, so we also  
16 use based on Gigerenzer and that people  
17 understand natural frequencies, so we're not  
18 using probabilities. We're using natural  
19 frequencies. If a 100 people have the surgery,  
20 about how many will have less pain after the  
21 surgery?

22 And we've actually tested a lot of

1 different ways of asking those kinds of  
2 questions, whether it's just open-ended, whether  
3 you give ranges and this idea of giving -- where  
4 we ended up was these sort of -- they're not  
5 random numbers, they're 30, 50, 70, 90. Can they  
6 understand if it's 90? Actually, almost  
7 everybody will have better pain.

8           So we have tried to balanced that a  
9 bit and it's a knowledge question. So we  
10 definitely get feedback from some folks who are  
11 -- oh, I'm going be tested. Or I don't want my  
12 doctor to look bad.

13           And what we try and do is emphasize  
14 even in the questions, this is about how good are  
15 we doing a job of getting you the information  
16 that you need. And that sort of helps a bit with  
17 some of the acceptability and getting patients to  
18 fill them out.

19           And then we also get a lot of notes  
20 like I didn't get this -- you know, when we get  
21 the surveys back, I didn't know this. Can you  
22 give me the answers, you know? Like can somebody



1 send me the answers to these questions?

2 So that's the other thing we get back  
3 when we do the written surveys. So people want  
4 this information and they're not always getting  
5 it.

6 CO-CHAIR STILLE: All right, Becky,  
7 and then -- I think we'll start voting. We'll  
8 have the opportunity for some more specific  
9 questions as we go through the metrics.

10 MEMBER BRADLEY: I just want to  
11 clarify. The way I read the exclusions, so if a  
12 patient only did not answer three of the five  
13 knowledge questions, were they excluded from the  
14 survey? Because on the survey I didn't see an  
15 answer that said I don't remember. So they  
16 either had to answer it wrong or leave it blank.  
17 So I guess that just kind of spoke to me in terms  
18 of whether or not they were excluded because they  
19 weren't knowledgeable or they left it -- just  
20 skipped that question.

21 DR. SEPUCHA: You're right. So we do  
22 have -- they have to answer a certain number of

1 the questions in terms of missing data -- in  
2 order to get a knowledge score. And so they have  
3 to answer at least half of those. So yes, you  
4 have to actually answer three of the five.

5 So the issue about the not sure, so  
6 we've done these questions across lots of  
7 different topics and lots of different ways and  
8 we've often included a response option, I'm not  
9 sure. And what we find is that so many people  
10 use that that it actually lowers the knowledge.  
11 But they know. Like if you asked them to guess,  
12 they would guess the right answer, but they kind  
13 of use that almost too often and so we were  
14 getting sort of artificially low knowledge scores  
15 at the end of it.

16 So what we did is we actually took it  
17 out and that did increase the number of missing  
18 items but not much. And it ended up, I think,  
19 giving us a better sense of what people really  
20 did understand.

21 MEMBER BRADLEY: And I guess my point  
22 is that this is new knowledge. It's for

1 patients. And given the age and the population,  
2 we know new learning is more difficult to retain  
3 than old learning. And so two years after you've  
4 been given a survey or a set of information, it  
5 may be difficult. They may have gotten it, but  
6 they really don't remember it and so it might  
7 speak more to the tool or the way the information  
8 is provided than to whether or not the provider  
9 informed the patient.

10 DR. SEPUCHA: I think that's  
11 definitely a potential challenge with this. You  
12 know, that said, the sample that we did have in  
13 here where we have four different sites, one of  
14 whom had really routine process of getting  
15 patients decision aids, we surveyed them about a  
16 year after their surgery, and there was a clear  
17 signal that the knowledge scores were higher in  
18 that site. Whether they would have been even  
19 higher if we had surveyed them earlier, I think  
20 there's probably a good chance it would have  
21 been, but we were still able to actually detect  
22 sort of the site that did better or worse a year

1 later.

2 CO-CHAIR STILLE: Okay, any more  
3 burning general questions before we start to  
4 progress through. Okay.

5 Let's start to talk about evidence.  
6 Ready to go.

7 MS. QUINNONEZ: We are now voting on  
8 Measure 2958, Informed Patient-Centered Hip and  
9 Knee Replacement Surgery. Voting is now open for  
10 evidence. Rationale supports the relationship of  
11 the health outcome or PRO to at least one health  
12 care structure, process, intervention, or  
13 service. Option No. 1 is yes, Option No. 2 is  
14 no. Looking for one more vote. All votes are in  
15 and voting is now closed.

16 The results are 95 percent voted yes;  
17 5 percent voted no.

18 CO-CHAIR STILLE: Okay. So we'll talk  
19 for a moment about gap. I know there's been a  
20 little discussion on this already, but any other  
21 comments about performance gap as presented?

22 Becky, did you have a comment? Okay.

1 Sam?

2 MEMBER BIERNER: My question is this  
3 was not really tested in a group of patients  
4 other than patients at your university hospital,  
5 is that right? They don't seem to be very  
6 ethnically diverse and kind of match to  
7 characteristics of the U.S. population.

8 DR. SEPUCHA: So there were three  
9 different hospitals that we had and one was a  
10 community site -- they were sampled. So it was  
11 people responding to an ad in the newspaper. So  
12 they were potentially treated at different  
13 places. So it's not just one center.

14 MEMBER BIERNER: But your sample is  
15 not representative of the U.S. population?

16 DR. SEPUCHA: Yes, it was not a  
17 nationally-representative sample.

18 MEMBER BIERNER: And you didn't test  
19 anything in -- this was only done in English.  
20 You didn't have the Spanish version?

21 DR. SEPUCHA: We didn't have the  
22 Spanish version that we've tested. We have a

1 Spanish version that's available of the measure,  
2 but it hasn't been used widely.

3 CO-CHAIR STILLE: Sherrie.

4 MEMBER KAPLAN: This is for Sarah.  
5 This is another one of these -- Helen. This is  
6 for you. Specially designed question for you.

7 Because you are not phasing yet, the  
8 measure is at an early phase of development where  
9 there wouldn't be expected to be a ton of data,  
10 for example, on geographic diversity or  
11 disparities or whatever, help us understand what  
12 we're to do with issues of an evidence of  
13 performance gap when the measure is in this stage  
14 of development?

15 DR. BURSTIN: Hi, everybody. So it's  
16 a great question. And I think this comes up a  
17 lot. And I think the question would be if the  
18 performance gap can't be provided by the actual  
19 measure developer in terms of the work they've  
20 done, can you look to the literature is perfectly  
21 acceptable as well.

22 In addition, you can find this matches

1 the performance gap, it can also just be  
2 variation, so you don't just have to have a gap  
3 in performance but variation across providers is  
4 also applicable, as well as any indication of  
5 disparities as another way of looking at  
6 fulfilling this particular subcriteria. Does  
7 that help?

8 MEMBER KAPLAN: Follow up on that.  
9 Would you consider evidence that it's mutable and  
10 responsive to efforts to change the measure like  
11 a quality improvement initiative that got  
12 implemented as being evidence that there is some  
13 room for improvement?

14 DR. BURSTIN: One would think that  
15 logically, if you could move a measure, you've  
16 demonstrated there could be variation. It also  
17 goes to the conceptual basis for the outcome,  
18 which you guys just did. So I would think that  
19 would be a logical approach. But also, I would  
20 think there's a fair amount in the literature  
21 about the variation. We already know about  
22 patients' understanding of these conditions and

1 differences and choosing or not choosing to have  
2 preference-sensitive conditions. That should  
3 also potentially weigh in to the performance gap  
4 and variation.

5 CO-CHAIR STILLE: Great. Any other  
6 discussion about gap? Okay. Let's vote.

7 MS. QUINNONEZ: Voting is now open for  
8 importance to measure and report performance gap  
9 for Measure 2958, data demonstrated considerable  
10 variation of overall less than optimal  
11 performance across providers and/or population  
12 groups. Option No. 1 is high. Option No. 2 is  
13 moderate. Option No. 3 is low. Option No. 4 is  
14 insufficient.

15 Looking for just one more vote. All  
16 votes are in. And voting is now closed.

17 The results are 5 percent voted high;  
18 74 percent voted moderate; 21 percent voted low;  
19 and 0 percent for insufficient.

20 CO-CHAIR STILLE: Okay, now we'll  
21 briefly talk about reliability. I know we've  
22 already had some discussion, but any other



1        comments about reliability?

2                    MS. SAMPSEL:  She struggled with that,  
3        did anybody else notice that?

4                    CO-CHAIR STILLE:  She tried so hard.

5                    MEMBER KAPLAN:  I did.  I really  
6        struggled.  Did I try not to say anything?  Yes.  
7        So because I raised the issue of if this is going  
8        to be used as a practice level variable, if it's  
9        going to be used as a practice level measure,  
10       right now it doesn't look like the analysis that  
11       was done demonstrates that there is inter-class  
12       correlations.  There is less within them between  
13       practice variation.

14                   On the other hand, there's pretty  
15        solid evidence that it actually can be used at  
16        the patient level.  So if the ultimate intent and  
17        I don't mean to lead you in a direction here, but  
18        if the ultimate intent is to use this as a  
19        practice level, do you anticipate that that is  
20        the next move for these data or for the  
21        evaluations you put this through?

22                   DR. SEPUCHA:  So yes.  I mean I do

1 think that's where we're going and getting more  
2 data to do that.

3 I'm wondering if I just clarify like  
4 what we had done in that last one because I  
5 thought -- so there's one thing where we look at  
6 practice level reliability which we might have  
7 done the wrong --

8 MEMBER KAPLAN: Right, but it was a  
9 split half reliability and it was within the  
10 practice. It was within practice variation, not  
11 between practice variation, so in that sense you  
12 look for the thumb print across patients within  
13 the practice and then compare between practices.  
14 And that isn't what was done. But that could be  
15 a communication problem with some of the guidance  
16 you got. So I'm not sure at this stage in  
17 development of this measure that would be as much  
18 of a concern.

19 CO-CHAIR STILLE: I have a similar  
20 concern and I don't know since Helen is here  
21 maybe we can ask her input about what happens.  
22 But in terms of if practices -- if measures are

1       meant to compare practices, but the initial data  
2       really doesn't quite have that level of analysis  
3       yet kind of where to go.

4               DR. BURSTIN:   I mean, I think  
5       basically we need analysis at the level at which  
6       the measure is intended.  I don't know if there's  
7       a higher level of analysis for which the testing  
8       done to date would be applicable system or  
9       something like that, but that is our requirement,  
10      just like, I guess, you talked about probably for  
11      the last two days.

12             MEMBER KAPLAN:  Let me follow up on  
13      that because of the number of practices, it's not  
14      like it's a big available measure where it's been  
15      gathered in an environment where you would expect  
16      that analysis to be able to be done and if it was  
17      not, then okay, with the measure's developer we  
18      would ask them and it would be a legitimate  
19      question to ask for that.  In this case, it's not  
20      widely available yet and if it's not being  
21      routinely collected, then the sort of between  
22      versus within practice variation is not like you

1 have 400 practices to look at, so that's why I'm  
2 struggling with we can -- what can we ask  
3 legitimately of a measure in this stage of  
4 development?

5 DR. BURSTIN: And this is often the  
6 case with new and emerging measures you're not  
7 going to have in widespread use, so this is a bit  
8 of a Catch-22 because we also find that it is  
9 then difficult to get measures into the more  
10 widespread use if they're not NQF endorsed. So I  
11 think you should look at what you have available  
12 to you in terms of the data that have been  
13 submitted, knowing it's not going to be for a  
14 large number of practices because it is a new  
15 measure and see if that's something you could  
16 live with as they begin to gather more  
17 information as the measure is out.

18 CO-CHAIR STILLE: Great. Thanks.  
19 Thanks for that clarification. Any other  
20 comments on reliability? Okay, Desi, let's vote.

21 MS. QUINNONEZ: Voting is now open for  
22 reliability of measure 2958 including precise

1 specifications and testing. Option 1, high;  
2 Option 2, moderate; Option 3, low; and Option 4,  
3 insufficient.

4 All votes are in and voting is now  
5 closed. Zero percent voted for high; 58 percent  
6 voted for moderate; 37 percent voted low; and 5  
7 percent voted insufficient.

8 CO-CHAIR STILLE: Okay, validity now.  
9 Again, we've had considerable discussion about  
10 validity, but any other comments that people have  
11 thought about? Seeing none, let's vote.

12 Oh, Sherrie, one more.

13 MEMBER KAPLAN: Yes, again, well, it  
14 wouldn't be -- it's like my bathroom scale  
15 analogy. You wouldn't expect -- my bathroom  
16 scale is consistently wrong, but you wouldn't  
17 expect a measure to be inconsistently correct.  
18 So it's really hard given what we just did with  
19 the reliability findings to then make the case  
20 that then the validity is okay.

21 On the other hand, having said that,  
22 this is one of the few measures I've actually

1       seen that actually does look like it's responsive  
2       to efforts to change the measure to quality  
3       improvement efforts.

4               And so in terms of responsiveness and  
5       the validity of a measure like this to kind of --  
6       when you actually test it against efforts to  
7       improve care, i.e., decision aids that improve  
8       shared decision making and the measure response  
9       to it, I'm really struggling with how to do this  
10      one myself because I feel like this could be one  
11      of those very unusual examples of where we would  
12      love to have had a different reliability  
13      standard, but the validity standard may actually  
14      be shifting around on us.

15              CO-CHAIR STILLE:  Thanks.  Okay, let's  
16      vote.

17              MS. QUINNONEZ:  Voting is now open for  
18      validity of measure 2958, including  
19      specifications consistent with evidence tests and  
20      threats addressed, exclusions, risk adjustment  
21      stratification, meaningful differences,  
22      comparability multiple specifications, missing

1 data. Option 1 is high. Option 2 is moderate.  
2 Option 3 is low. And Option 4 is insufficient.

3 Waiting for two more votes. All votes  
4 are in and voting is now closed. Zero percent  
5 voted high; 68 percent voted moderate; 26 percent  
6 voted low; and 5 percent voted insufficient.

7 CO-CHAIR STILLE: Okay, so it passes  
8 on validity. Next up, feasibility. We haven't  
9 had too much discussion on feasibility, but I  
10 don't know how many issues there are.

11 Becky, you're up first.

12 MEMBER BRADLEY: Yes, I just wanted to  
13 ask about the burden of collecting the data. It  
14 seems that this would be done by practices, I  
15 guess, but as you all studied this information,  
16 how much time was required in collecting the  
17 responses and is this something that physicians  
18 and clinical practices would have already have  
19 people designed to do or is this would be an  
20 added burden in terms of feasibility?

21 DR. SEPUCHA: So I think it depends a  
22 lot on the practice. In terms of burden on the

1 patient, the six items were very -- it took a few  
2 minutes. It didn't take very long, so it wasn't  
3 very burdensome from the patient perspective.

4 But in terms of an additional survey, it would  
5 require someone to either mail it out or email it  
6 out depending on the method that they're going to  
7 be using to do that. So it's -- and maybe a  
8 reminder or two. When we've done this, we've had  
9 very good response rates with some reminders. So  
10 patients are happy to fill this out. I think  
11 they like talking about their experiences with  
12 these decisions. So we found a pretty good  
13 response rate for that. But I think it depends  
14 on some practices are going to have more probably  
15 resources in place where they're already  
16 assessing either patient-reported outcomes, post-  
17 surgical, or pre-surgical. So they might have  
18 that -- an easier way to sort of integrate these  
19 questions into things that they're already doing.

20 MEMBER BRADLEY: So are you  
21 anticipating that there would be a vendor that  
22 would collect the information and analyze it at



1 the practice level or are there -- how would the  
2 information be used for performance improvement?

3 DR. SEPUCHA: So I think the practices  
4 could collect it themselves and then get that. I  
5 don't know if there's a vendor that probably  
6 could be doing this as well. I don't think we've  
7 figured out exactly yet how that will --

8 MEMBER BRADLEY: Okay.

9 CO-CHAIR STILLE: Okay, other  
10 feasibility comments? Let's vote.

11 MS. QUINNONEZ: Voting is now open for  
12 feasibility of measure 2958, including data  
13 generated during care, electronic sources, and  
14 data collection can be implemented. Option 1 is  
15 high. Option 2 is moderate. Option 3 is low.  
16 And Option 4 is insufficient. Waiting for two  
17 more votes.

18 MS. THEBERGE: David, we need your  
19 vote. There it is. Thank you.

20 MS. QUINNONEZ: All votes are in and  
21 voting is now closed. Zero percent voted high;  
22 79 percent voted moderate; 16 voted low; and 5

1 percent voted insufficient.

2 CO-CHAIR STILLE: All right, the  
3 usability and use. Given that it hasn't been  
4 used much yet, but how usable do people feel it  
5 is.

6 Sherrie, did you have a comment?

7 MEMBER KAPLAN: Yes, I have a  
8 question. How do you see this measure being  
9 used?

10 DR. SEPUCHA: So I think similar to  
11 what we were thinking about for the measure  
12 previously discussed on shared decision making.  
13 The idea would be whether it's accountable care  
14 organizations. There's lots of things in hip and  
15 knee replacements specifically around bundled  
16 payments for these things. So thinking about a  
17 way to have this incorporated into programs that  
18 are looking at the quality of the surgical  
19 process of care. And so understanding, you know,  
20 not just what the rates of surgery are or the  
21 rates of readmissions, but looking at were they  
22 the right person in the operating room in the

1 first place, were they well informed, did they  
2 have a clear preference for it? So having that  
3 kind of bundled in in part of programs that are  
4 looking at that.

5 There are certain folks that have sort  
6 of approached us about using them that are payer  
7 groups who either have sort of distinction  
8 programs or recognition programs for practices or  
9 providers who were delivering joint replacement  
10 surgeries. And so this could go into that sort  
11 of bundled kind of measures that they're going to  
12 be using with respect to those programs.

13 MEMBER KAPLAN: Accountability versus  
14 quality improvement?

15 DR. SEPUCHA: I think it would  
16 probably be a little bit of both. You know,  
17 right now, it's been only used so far in quality  
18 improvement scenarios, but I think there's  
19 interest in thinking about it for accountability.

20 CO-CHAIR STILLE: Jennifer.

21 MEMBER BRIGHT: So I just want to make  
22 a comment that this is where I get really

1 uncomfortable and I know we're in, as a  
2 committee, we're in unique, uncharted territories  
3 and we're like out there with the machete in the  
4 jungle trying to carve a path through, but I get  
5 really uncomfortable when we're considering a  
6 measure that's really only been looked at within  
7 a practice and has high value, I think, from a QI  
8 perspective. But then we're immediately jumping  
9 and we know the environment into which this gets  
10 released is one that's hungry for an answer of  
11 what do we pay for. That's when I literally get  
12 heart palpitations because I think I want to see  
13 measures like this in widespread use.

14 And I totally get what you're saying,  
15 Helen, about there's this doorway that we are  
16 helping to facilitate, right? But I get really  
17 nervous because we're releasing it into an  
18 environment, a payment conversation environment  
19 that's not ready for this yet.

20 And I know we can't talk about  
21 guidance, but if we're really only evaluating  
22 this based on study data that says it's got high

1 value for quality improvement, we should be  
2 evaluating it for quality improvement only and  
3 not saying that this has any applicability to  
4 looking at accountability. I just really  
5 passionately feel like we're in dangerous  
6 territory if we say one thing and do another.  
7 Sorry.

8 CO-CHAIR STILLE: Thank you. Sherrie,  
9 one more?

10 MEMBER KAPLAN: It does say on the  
11 form under criterion 4 it says "current uses  
12 publicly reported, no; current use and  
13 accountability or planned use and accountability"  
14 and it says no. But then it says yes and no  
15 under the current use and accountability. Is  
16 that a typo? That's why I asked you the  
17 question.

18 DR. SEPUCHA: Sorry, where?

19 CO-CHAIR STILLE: The one on the  
20 screen just says no.

21 MEMBER KAPLAN: Well, in the form I'm  
22 staring at it's both boxes are checked.

1           MEMBER BIERNER: You make reference to  
2 the Alliance, a regional group in Wisconsin. Are  
3 they using this?

4           DR. SEPUCHA: So they've got a  
5 QualityPath program. So they encourage providers  
6 or practices to sign up for it and get credit and  
7 as part of that, they have to use decision aids  
8 and measure decision quality, so use the decision  
9 quality instruments from which this measure has  
10 been derived. There wasn't a measure available  
11 for them to use. They encouraged the providers  
12 to use the decision aids.

13           MEMBER BIERNER: I'm looking at their  
14 website document. It's very explicit that  
15 they're using it to make decisions about who will  
16 -- who is in their network and whether these are  
17 preferred providers and things.

18           CO-CHAIR STILLE: Okay. Lisa?

19           MEMBER SUTER: So similar to the last  
20 measure, have you -- I know patients and  
21 providers were involved in the development. Have  
22 you gone back to them about how they would use

1       this information and whether they're using this  
2       information? I know patients said that they  
3       would have liked their doctors to give them this  
4       information, but that might actually be  
5       problematic after the fact. It could have --  
6       opening Pandora's box downstream saying your  
7       doctor really didn't give you a lot of  
8       information about the surgery they put you  
9       through. So there are some challenges with when  
10      you collect this information and how it's  
11      integrated into practice. Have you talked to  
12      stakeholders, patients, and providers about how  
13      they would use it?

14               DR. SEPUCHA: Yes, we've run a couple  
15      of focus groups with patients for hip, knee, and  
16      back surgery. And the idea there was to try and  
17      figure out what from the surveys what information  
18      would they want to understand in order to either  
19      evaluate providers or make sense of who they  
20      might want to go see.

21               So the knowledge was pretty straight  
22      forward and I think they -- in terms of

1 interpretation of Provider A's average knowledge  
2 scores of the patient with such and such and  
3 Provider B was something else. I think they  
4 really kind of got the sense, oh, they must have  
5 -- actually, what they said is they must have a  
6 really good nurse who's helping people get  
7 information there with that surgeon versus that  
8 surgeon. So they really like to see that  
9 information.

10 What was interesting was the feedback  
11 that we had given them on the -- how often  
12 providers -- you know, patients who had surgery  
13 preferred it. And the way they interpreted that  
14 is providers who maybe didn't have such a high  
15 percentage there so who were actually giving  
16 surgery people who didn't have a clear preference  
17 for it, they interpreted that as oh, that doctor  
18 is really good at talking people into having  
19 surgery which is actually in a sense what this is  
20 about.

21 So we have gotten a little bit of  
22 feedback of what kind of things, how do they



1 interpret this information, what they would want  
2 to do, how would they want to use it. And I  
3 think so they liked having that information as  
4 well as wanting information, obviously, about  
5 sort of the health outcomes, so how do people  
6 feel about the surgery if they've had it as  
7 another component of it. But we haven't done  
8 anything in terms of thinking about how you would  
9 release this publicly or what we would do, with  
10 the exception of Dartmouth which would publish  
11 this on their website. They put their knowledge  
12 scores in the distribution of that their patients  
13 wanted. But that was just their own breast  
14 center website.

15 CO-CHAIR STILLE: Okay, Linda, real  
16 quick. We need to move on.

17 MEMBER MELILLO: I just have a newbie  
18 type question. Is there any way that this  
19 committee can put limitations on the use of a  
20 measure pending later review?

21 DR. SEPUCHA: No.

22 MEMBER MELILLO: Okay.

1 CO-CHAIR STILLE: Okay, let's vote on  
2 usability and use.

3 MS. QUINNONEZ: Voting is now open for  
4 usability and use of measure 2958 including  
5 accountability, transparency, improvement,  
6 progress demonstrated, benefits outweigh evidence  
7 of unintended negative consequences. Option 1 is  
8 high. Option 2, moderate. Option 3, low. And  
9 Option 4, insufficient information. Just waiting  
10 for one more vote.

11 MS. THEBERGE: David, we need your  
12 vote. David, are you on the line? I think he  
13 stepped away.

14 MS. QUINNONEZ: Okay, votes are in and  
15 voting is now closed. Zero percent voted high;  
16 50 percent voted moderate; 33 percent voted low;  
17 and 17 percent voted insufficient information.

18 CO-CHAIR STILLE: Okay, so consensus  
19 not reached on that. Okay. And then finally,  
20 overall, let's vote.

21 MS. QUINNONEZ: Voting is now open for  
22 overall suitability for recommendation for

1 endorsement of measure 2958. Option 1 is yes.

2 Option 2 is no.

3 MS. THEBERGE: One more check, David,  
4 are you there?

5 MS. QUINNONEZ: Waiting for one more  
6 vote. Can everyone resubmit their votes one more  
7 time? Thank you. All votes are in. And voting  
8 is now closed. Fifty-six percent voted yes and  
9 44 percent voted no.

10 CO-CHAIR STILLE: So consensus not  
11 reached on suitability. Okay. Public comments.  
12 Let's open the line.

13 MS. THEBERGE: Operator, can you open  
14 the line for public comments?

15 OPERATOR: Yes, ma'am. At this time,  
16 if you would like to make a comment, please press  
17 1. At this time there are no public comments  
18 from the phone lines.

19 CO-CHAIR STILLE: Okay.

20 CO-CHAIR PARTRIDGE: We've had a mini-  
21 break, right?

22 CO-CHAIR STILLE: We've had a mini-

1 break. We can --

2 CO-CHAIR PARTRIDGE: I know we're  
3 going to lose people at noon. Do you feel the  
4 need for a formal break or can you just all slip  
5 out? We want to add one brief item to the  
6 agenda. Sarah wants to talk to us a little bit  
7 about something else NQF is doing.

8 So if that's okay, we'll just stay in  
9 place and keep going.

10 CO-CHAIR STILLE: Okay.

11 CO-CHAIR PARTRIDGE: Sarah, it's  
12 yours.

13 MS. SAMPSEL: And so Helen will be  
14 given the opportunity to add to this as well, but  
15 based on this conversation and then, you know,  
16 kind of it was very interesting to hear all of  
17 your comments, we wanted to give you an overview  
18 of another project that NQF is working on and  
19 really kind of started the conversations between  
20 NQF and Jack and Karen and others in this shared  
21 decision making space.

22 So at the end of last year, beginning

1 of this year, we started a project funded by the  
2 Gordon and Betty Moore Foundation looking at the  
3 potential application of a national certification  
4 program for decision aids. And so the project  
5 staff team, as led by Helen and then myself and  
6 Andrew Anderson who has conveniently left, but  
7 anyways, we are convening a group towards the  
8 latter part of this month to talk about what  
9 those certification standards might be, as well  
10 as what the NQF process could potentially be  
11 funding, etcetera. And then part of that  
12 conversation as well is starting to talk about  
13 how do you translate decision aids and this whole  
14 decision making process into performance  
15 measures.

16 And so it was kind of an interesting  
17 opportunity when Jack and Karen indicated, and  
18 we've been talking to them for a couple of years  
19 about as they've been moving their measures  
20 through the process. And so wanted, one, you to  
21 be aware that a lot of the notes that I've been  
22 taking are kind of -- so when we talk to this

1 other panel say these are some of the things and  
2 some of the challenges, but also opportunities  
3 that we're going to have to start looking at,  
4 translating some of these really complex items  
5 into performance measures for shared decision  
6 making.

7 So first of all, I just wanted to  
8 thank you all because it was very enlightening to  
9 hear some of the comments, the questions, and a  
10 little bit of the pushback on what we would then  
11 turn into a report on developers. If you're  
12 thinking about doing these, these are some of  
13 your additional considerations.

14 At the same time, I just wanted to  
15 make sure you were all aware of that project  
16 going on. You can sign up for project alerts like  
17 you do anything else on our web site. But we  
18 really find it to be -- I mean at least I do,  
19 extremely interesting, extremely novel, but you  
20 know, some of these conversations as well, I  
21 think, are going to help push us in thinking  
22 stronger about it. So it's been great to have

1 the patient input here, but then certainly from  
2 you folks who are in practice, going to be trying  
3 to turn these around and into use and thinking  
4 about how we would then assess accountability and  
5 certainly QI in the future.

6 Helen.

7 DR. BURSTIN: Just one quick comment  
8 in response to Jennifer's comments and others. I  
9 think this is very much a sense that we recognize  
10 these measures of decision quality are going to  
11 be, likely to be very important as we look to the  
12 very different payment models that pay for value  
13 over volume. And so thinking about how they  
14 could be incorporated into future alternative  
15 payment models, etcetera, we recognize this is a  
16 future tense discussion.

17 I just want to thank the committee for  
18 kind of helping us think these issues through.  
19 The panel that will meet later this month will  
20 actually put forward a set of standards that  
21 we'll put out for comments that we should  
22 explicitly share with this committee what those

1 standards for those decision aids would look like  
2 because I think a lot of you would find that  
3 really interesting. And then actually think of a  
4 process of how we'll actually bring those  
5 decision aids, evaluate them and try to actually  
6 certify ones that meet a standard as the standard  
7 is done. And then the logical next step of that  
8 if you have decision aids, you logically want  
9 some measures that will incorporate the use of  
10 those decision aids.

11 So there is --- this is part of a  
12 broader strategy, but thank you for kind of  
13 helping us along this journey because this was  
14 really informative. And we recognize these  
15 issues of it is always difficult when we have new  
16 and emerging areas, either when evidence is  
17 limited, not that the evidence is contrary, it  
18 just isn't there yet. Or when we have new  
19 measures where the testing is minimal because,  
20 frankly, it's new and it's hard to get people to  
21 do a lot of sites of testing of a new measure.  
22 So those are issues we will continue to explore.



1           We've tried multiple ways of bringing  
2   in measures in the early stages of development  
3   for a quick early check that have generally not  
4   worked very well. We had a panel convened to  
5   actually help us think through whether we should  
6   actually endorse measures for their intended use,  
7   should we say this measure is only QI, this  
8   measure is only accountability? And ultimately  
9   the decision was there's just not enough science  
10   on which to base which ones go which direction at  
11   this point in time at least. We'll continue to  
12   look at it, but appreciate your willingness to  
13   look at some very new and I think important  
14   concepts that we want to keep moving forward even  
15   if not always immediately ready and hopefully the  
16   developers can share some additional information  
17   back with you as you move forward.

18           MEMBER KAPLAN: Am I understanding you  
19   that you're going to evaluate decision aids and  
20   now are you transitioning into evaluating the  
21   quality improvement activities versus just the  
22   quality assessment?

1 DR. BURSTIN: No. What came out of  
2 our intended use panel that met was that we would  
3 not go down a pathway of bringing in measures  
4 just for quality improvement. There are  
5 thousands of them out there. They don't  
6 necessarily need to go through a process like  
7 this. And so we decided that wasn't going to  
8 happen.

9 But at the same time there is, some of  
10 you may know this history, there's been an  
11 international group that has a set of standards  
12 called IPDAS around evaluating and setting  
13 standards for decision aids. Washington State  
14 has been required through legislation to actually  
15 begin evaluating decision aids, identifying which  
16 ones they're going to, in fact, standardize and  
17 use. So we've been building on the Washington  
18 State experience and trying to establish a set of  
19 national standards we would use to potentially  
20 bring in these decision aids so that as part of  
21 this value-base purchasing, as part of this sort  
22 of brave new world greater patient engagement,

1       there will at least be some sense that these are  
2       good decision aids that meet a certain standard.  
3       But not so much just for QI, but just broadly we  
4       think it's -- just like we bring in cost of  
5       research use measures, we don't consider those  
6       quality measures for accountability, but they're  
7       kind of information building blocks towards a  
8       bigger vision of value and so we view similarly  
9       this work on decision quality as fitting into  
10      that as well, that newer vision.

11               MEMBER SUTER: Hi, Helen, and I just  
12      wanted to ask. I apologize, I stepped out  
13      actually to speak with a prior measure developer.  
14      Is there a channel for people like this who bring  
15      a measure that we're enthusiastic about, but the  
16      specifications aren't quite settled and some of  
17      the data isn't there yet, although it sounds like  
18      she's partnering with a lot of organizations  
19      where she might be able to get some of the  
20      facility-level data.

21               Is there an accelerated process for  
22      them to come back through or -- I'm just

1       wondering, given that we've put so much effort  
2       into thinking through it, is there an accelerated  
3       process for something like that?

4               DR. BURSTIN:   So one of the reasons we  
5       made the shift to having standing committees was  
6       to have the capacity to have a group like you  
7       available.   So one question, you know, for Karen  
8       and her team will be how much they can do in the  
9       next couple of months to address those issues?  
10      They have until the end of the comment period as  
11      you know.   If there's anything they could bring  
12      back to the committee to move some of those kind  
13      of gray zone votes up, that's an option.   But we  
14      also potentially could convene you -- I'm looking  
15      to Elisa who is really the boss of process, to  
16      make sure I don't say anything she would --  
17      she'll kick me.   But you know, because you  
18      already convened as a standing committee, we  
19      could potentially do a webinar in X period of  
20      time where we would say you've already gone  
21      through all these criteria.   Let's just go back  
22      and look again at the additional testing and

1 maybe just pick up the evaluation from there.  
2 Because again, we don't want to have to make  
3 these measures sit out there for an eternity  
4 waiting for our next call.

5 So we've been working with CMS to just  
6 allow us to have this capacity of you guys are  
7 here, you know -- the idea of bringing a measure  
8 like that to a new group would make no sense.  
9 You've already thought it through. You raised  
10 all the issues. Can they address the issues,  
11 bring it back to them, and hopefully get it  
12 blessed in a shorter time period.

13 MEMBER BRADLEY: Can I just ask? The  
14 scope of the work that you're doing with CMS, is  
15 it limited to procedures or does it extend to  
16 other informed decisions that patients and  
17 families and care givers make like -- because  
18 it's kind of counter intuitive to the whole  
19 concept of patient choice that CMS has put out  
20 there in the past where providers aren't supposed  
21 to provide too much information, that patients  
22 have the right to just get a list and choose.

1                   So I'm wondering kind of where that  
2                   overlap is, informed decision versus mission  
3                   choice?

4                   DR. BURSTIN: Interestingly again for  
5                   some of these new and innovative areas, we often  
6                   will go outside of government give us the  
7                   greatest latitudes to really please the Gordon  
8                   and Betty Moore Foundation supporting this work.

9                   I will say though that as part of an  
10                  interesting decision about a year ago, CMS put  
11                  forward a payment rule, a notice of payment  
12                  around the use of low dose CT scanning for  
13                  smokers. And Lisa may know about this because a  
14                  lot of this is about informed consent of whether  
15                  you would approach a smoker to have low dose CT  
16                  scanning. And the way it was put forward by CMS  
17                  was only if done in the done in the context of  
18                  use of an approved decision aid, that they  
19                  specific want for one of these very preference,  
20                  sensitive decisions that there be that  
21                  discussion.

22                  I've heard similar discussions around

1 potentially PSA screening. Again, as you look  
2 toward some of these things where the black and  
3 white of evidence is fuzzier and it really does  
4 come into context of values and preferences, how  
5 that all gets incorporated and so we're actually  
6 going to work through at the committee, the  
7 example of taking the lung CT screening measure  
8 and working it through with the committee to  
9 think through what that process looks like. But  
10 it is definitely a new space and we think it's  
11 important. We step into it because we think --  
12 because you look at the broader context of  
13 quality and patient-centered quality and  
14 particularly it's hard to imagine doing any of  
15 that without greater engagement of patients and  
16 their preferences.

17 CO-CHAIR PARTRIDGE: Okay, I'm now  
18 going to welcome in person representatives of the  
19 University of Colorado Center for Bioethics and  
20 Humanities. We apologize for keeping you  
21 waiting. Please do join us at the table.

22 MS. SAMPSEL: And while Matt's coming

1 up, I'm just going to make a couple of comments  
2 and introductions. So Matt and his assistant  
3 cohort, Heidi, from University of Colorado as  
4 well, had submitted seven measures for  
5 maintenance review. And these measures were  
6 originally endorsed and approved for endorsement  
7 by a Disparities Committee a number of years ago.  
8 However, we no longer have the Disparities  
9 Standing Committee and the measures best fit in  
10 the portfolio for Person and Family Center Care.

11 However, this was also a recognition  
12 of this was a transition process because prior to  
13 Matt going to University of Colorado, he was with  
14 the AMA, so these measures changed their  
15 stewardship. When we received the submission for  
16 maintenance, this was a recognition of these  
17 might not be ready for kind of this full  
18 maintenance review because they hadn't been --  
19 there had been kind of a -- I don't want to call  
20 it a dead period, but kind of a sleeping period  
21 during a transition. I'll let Matt describe it  
22 how he would like to, but let's just say they



1       were sleeping for a bit. Therefore, there wasn't  
2       the level of data. There wasn't the level of  
3       information that I knew you were all going to  
4       look for in the continued and the maintenance of  
5       endorsement.

6               So rather than kind of forcing Matt  
7       and Heidi to pull together an incredible amount  
8       of data in an extremely short period of time, and  
9       through conversations with them, we thought it  
10      would be better to bring, have Matt come, given  
11      an overview of exactly what they're doing and  
12      then look to all of you and the kind of questions  
13      that we've had with our other measures over the  
14      past few days and few cycles of work to give that  
15      feedback on what will you want to see, where are  
16      there opportunities so that we can certainly look  
17      at these measures in their whole. So that's  
18      really kind of the background of why Matt's here  
19      and not -- and we're not looking for endorsement  
20      of those measures.

21              DR. WYNIA: Thank you. So it's a  
22      pleasure to be here and I expect to learn a lot

1 of really helpful stuff from you today. I should  
2 say I spent 18 years at the AMA as a staff  
3 person, so when a staff person at an organization  
4 like NQF says you know what you ought to do, you  
5 ought to come and present in front of the  
6 committee and ask them some of these questions.  
7 I take that very seriously, so thank you, Sarah,  
8 for providing excellent advice in hopefully  
9 moving these forward.

10 So I'm going to give you a little bit  
11 of background on this. I was told that the  
12 general rules of engagement were that measure  
13 developers got two minutes, but that we would get  
14 a little bit more than that. And I unfortunately  
15 feel like I'm going to need a little more than  
16 that because these are unusual measures.

17 So let me start with where these came  
18 from at the American Medical Association. We  
19 developed a program called a Ethical Force  
20 Program. Actually, John Eisenberg and Linda and  
21 Zeke Emanuel and I developed this program long  
22 ago. And the idea was to look at ethical

1 performance across the healthcare system. So we  
2 felt like organizations like the American Medical  
3 Association were pretty good at drawing up  
4 ethical guidance for patient-doctor interactions  
5 for that dyad. But that then doctors and  
6 patients and others were put into environments  
7 that made it easier or harder to live up to those  
8 ethical standards.

9 And so we wanted to know are there  
10 organizational standards for ethical performance  
11 that we could actually measure. And we worked on  
12 this with the Hospital Association, the Nurses  
13 Association, the Joint Commission, NCQA, CMS,  
14 AHRQ, patient organizations, most notably Myrl  
15 Weinberg from the -- what's her organization  
16 called? National Health Council and so on, so  
17 sort of many of the usual suspects.

18 And the idea was to look across the  
19 healthcare system and we looked at specific  
20 domains. We looked at privacy and incidentally  
21 this was pre-HIPAA, so Mike Fitzmaurice from AHRQ  
22 was on the oversight body at the time and took

1 some of the conversations around HIPAA, around  
2 privacy back into the conversation around the  
3 development of HIPAA for better or worse.

4 We talked about fair coverage  
5 decisions, health system reform and then we  
6 started thinking about health disparities and the  
7 way in which we frame health disparities and the  
8 role that our group could take was to look at  
9 effective communication for all patients. We  
10 felt like rather than trying to measure cultural  
11 competence which was the language everyone seemed  
12 to be using at that time, seems a little dated  
13 now, but nevertheless, we felt like the way that  
14 we should measure whether organizations were  
15 doing a good job of creating an environment in  
16 which minority patients, people with limited  
17 English proficiency, people with low literacy,  
18 were getting excellent care would be to look at  
19 the communication climate in those organizations.

20 So in 2006, in collaboration with the  
21 American Hospital Association, we did a national  
22 project where we traveled to a bunch of hospitals

1 and looked for promising practices in patient-  
2 centered communication. This was funded by the  
3 Commonwealth Fund. And what came out of it were  
4 a set of domains of quality of communication  
5 climate in healthcare organizations. We brought  
6 those back to the oversight body which again was  
7 this 21-member group with stakeholders from  
8 across the healthcare system and they voted on  
9 these. And it was a fairly elaborate and intense  
10 consensus process. We voted on whether each of  
11 these domains and then each of the content areas  
12 within the domains were universally important, in  
13 other words, important to all types of  
14 organizations, not to only one type of  
15 organization in healthcare, whether they were  
16 feasible to achieve, whether excellent  
17 performance was realistic to achieve, and whether  
18 it would be measurable. And each of these were  
19 measured on a ten-point scale, zero to ten. The  
20 average had to be seven and if anyone voted three  
21 or lower, it was eliminated from consideration.

22 So the consensus in this instance

1 included giving everyone on the panel a veto. So  
2 this was sort of the first stage of validation in  
3 the sense of content validation of what it was we  
4 were going to be asking organizations to try and  
5 live up to and measure.

6 In 2010, we had developed a  
7 measurement tool kit looking at these nine  
8 different domains. And we tested it in a set of  
9 hospitals around the country and published those  
10 results.

11 In 2011, we started training  
12 consultants to help hospitals, primarily,  
13 although some large groups have also used these  
14 tools, but mostly it's been hospitals and so we  
15 trained consultants to help hospitals use these  
16 tools. We did this incidentally, after a period  
17 of experimentation where we just gave people the  
18 tool, the tools, and said here's how you use  
19 them. And it turns out that is an ineffective  
20 model of spread. If you just sort of make the  
21 tools available which they are, these are  
22 publicly available. Anyone can still use them

1 for free, they're online, but the reality is, it  
2 is a rare organization that will take a 360-  
3 evaluation tool kit off the web and take it home  
4 and use it.

5 So we trained consultants to help  
6 people use these tools and the other thing that  
7 does is when they work with a consultant, we have  
8 some assurance of the quality of data that they  
9 are gathering. And so we've created a  
10 benchmarking database which only comprises data  
11 gathered by organizations working with our  
12 authorized consultants. And that allows us to  
13 give hospitals these nine domain scores and all  
14 of the breakdowns which I'll show you in a moment  
15 alongside a benchmark score of what other  
16 hospitals using consultants have scored in that  
17 domain.

18 In 2012, the Disparities Panel  
19 endorsed seven of our nine domains. And I should  
20 say I'll come back to this at the end. We sort  
21 of brought it together, we brought it forward as  
22 a package to endorse the 360 assessment. And the

1 recommendation at the time was you know, we  
2 should look at each of the domain scores  
3 separately which would be a little bit like  
4 taking the CAHPS survey and breaking it into four  
5 or five domains and saying we're going to endorse  
6 it four times. And that may or may not have been  
7 the right way to do it, but that was the  
8 recommendation that we got at the time. So seven  
9 of our nine domain scores were endorsed. Two of  
10 them were not. And I can talk more about why  
11 that was if you'd like.

12 I will say a point of pride, there  
13 were 12 measures endorsed that year for  
14 disparities, 7 of which were in our C-CAT tool.  
15 So we felt like we had made a good contribution.  
16 Unfortunately, we had a number of hospitals that  
17 started to use this and then we got a new CEO at  
18 the American Medical Association. And with the  
19 reorganization of the organization, I was moved  
20 into a different area and the continued support  
21 for the C-CAT was really brought into question.  
22 And as a consequence, people stopped using it.



1 Not that it wasn't still available to use, but  
2 when the consultants realized that the support  
3 for this may disappear and/or the benchmarking  
4 database may no longer be available, their  
5 incentive to get hospitals to use it really  
6 disappeared. So we had about a two-year time  
7 frame during which almost no one used this. I  
8 think we had one assessment in two years. So  
9 that's the dormant period that Sarah referred to.

10 In 2015, I moved to the University of  
11 Colorado or began my move to the University of  
12 Colorado and started negotiating to transfer  
13 ownership of the C-CAT from the AMA to my center  
14 at the university. And in January of this year,  
15 basically, we relaunched the C-CAT tools.

16 So these are the nine domains of the  
17 C-CAT tool kit and I've put a star next to those  
18 that were NQF endorsed. The community engagement  
19 domain and the data collection domain are the two  
20 that were not endorsed, but as you'll see,  
21 performance evaluation, literacy, language  
22 services, cross cultural communication, patient

1 engagement, and shared decisions, work force  
2 development, and leadership commitment domains  
3 were all endorsed in 2012.

4           This is just the one table that's sort  
5 of the most salient perhaps from the validation  
6 study. And I'll just highlight one thing because  
7 there's a lot of data here. We looked at  
8 performance in each domain and whether it  
9 correlated with patient belief that they were  
10 receiving high quality care; patient trust in the  
11 organization in the sense that both the  
12 organization would keep things private which is  
13 you might think a completely unrelated measure of  
14 trust in an organization to the things we're  
15 looking at. But it turns out that trust in an  
16 organization is pretty strongly correlated with  
17 effective communication in almost all of these  
18 domains. So a five-point change. This is a 100-  
19 point scale. A 5-point change in the health  
20 literacy domain corresponds to a 40 percent  
21 increase in the odds that patients will believe  
22 they're getting high-quality care. Twenty-eight

1 percent increase in odds that they'll say their  
2 medical records are kept private by that  
3 organization and about a 27 percent reduction in  
4 the odds that they would say this organization  
5 would hide their mistakes from me. So think of  
6 that one, that's obviously reversed -- you  
7 reverse code that if you were looking at that  
8 positively. But that's again a measure of trust.  
9 Will this organization be honest with me if they  
10 made a mistake in my care.

11 So we had quite strong correlations  
12 with a couple of exceptions, in particular, that  
13 data collection was not related which might not  
14 be surprising. Whether the organization is  
15 collecting high-quality data on patient race,  
16 ethnicity, language, etcetera may not -- there's  
17 not a good reason to believe that that would be  
18 particularly related.

19 In any event, these are the tools in  
20 the tool kit. So this is a 360 evaluation of the  
21 organization. There is a patient survey. There  
22 is a staff survey and incidentally, it's an all-

1 staff survey. This is an important point because  
2 clinicians have a different perspective on the  
3 organization than non-clinical staff do. In  
4 fact, non-clinical staff often have perceptions  
5 of the organization that are more reflective of  
6 where patients are coming from. So if you're  
7 talking to housekeeping and engineering and so  
8 on, the people who work in the cafeteria, they're  
9 going to have a different look at how the  
10 organization performs with regard to these issues  
11 than clinical staff do.

12 There is also an executive survey and  
13 a workbook that a QI team fills out related to  
14 policies and so on. I didn't highlight those  
15 because they don't go into the score. They go  
16 into the report that you get because they touch  
17 on the same issues so they're important in terms  
18 of quality improvement, but they don't go into  
19 your domain score.

20 The data collection process is a  
21 collaboration between the site, the consultant,  
22 and our staff on what the scope is going to be,

1 the time line, preparing surveys for  
2 distribution, deciding whose name goes on the  
3 cover letter, what logos go on the cover letter,  
4 that kind of stuff.

5 And then all of the analysis of the  
6 basic report creation is done by our staff and  
7 the consultants don't see this and the hospital  
8 doesn't see this. And that's on the cover  
9 letter, obviously, to the patients and to the  
10 staff.

11 Where IRBs have looked at this and not  
12 always is this required to be reviewed by an IRB,  
13 but in some instances it is. Where IRBs have  
14 looked at it, the thing they're most worried  
15 about is will staff say something in the comment  
16 section of their survey that will get back to  
17 their boss and end up getting them fired. So it  
18 actually has not been the patient survey that's  
19 been a concern. The patient survey is entirely  
20 anonymous, so it's unlikely that it could be tied  
21 back to an individual. But the staff surveys  
22 which are also anonymous, but unfortunately,

1       there's a lot of small pieces of organizations  
2       where it's hard to maintain anonymity despite  
3       efforts.

4               So the standard report, and I'll show  
5       you some pictures from it in the next slide or  
6       two, shows the domain scores in each of those  
7       nine domains compared to the benchmarks. It also  
8       shows executive survey and organizational  
9       workbook responses next to the relevant survey  
10      items.

11              I'll just give you a quick example.  
12      So you may have a policy on using teach-back as a  
13      means of addressing health literacy concerns.  
14      You may believe in your QI team that that policy  
15      is a pretty good policy and that people are  
16      following it. On the staff survey, it may be  
17      that many of the staff are unaware that that  
18      policy exists and/or that they are not using  
19      teach-back in their clinical practice and  
20      similarly in the patient survey, you may or may  
21      not see that patient's report having ever  
22      received a teach-back from their doctor at the

1 institution. So we tie these things together in  
2 the report. And we give guidelines for  
3 interpretation.

4 Consultants then often, not always,  
5 but often will supplement the standard report  
6 with their qualitative findings because they will  
7 often have additional services that they'll  
8 provide to a hospital, so they may do focus  
9 groups. They may do tracer methods. They may do  
10 other things which they'll then use to supplement  
11 the report and give recommendations for QI or for  
12 next steps for the organization.

13 I want to point out a quirk of this  
14 which is that we calculate the overall domain  
15 scores by combining the patient responses and the  
16 staff responses on similar items. So the teach-  
17 back item would be similar for patients and for  
18 staff or there would a teach-back item. We had  
19 combined those and used that score. And we give  
20 equal weight to patient experiences and to staff  
21 experiences. So even if you have a lot of  
22 patients who will fill out the survey, and

1 relatively fewer staff or vice versa, they weigh  
2 equally in the domain score.

3 We show people in the report both the  
4 patient and the staff broken out. But the score  
5 that was endorsed last time around is the overall  
6 score which is this -- supposed to be this 360  
7 score and I realize that is weird and that you  
8 probably don't have any other measures where  
9 you're taking data from -- not just multiple  
10 items from one survey and combining them, but  
11 here we are combining data from two different  
12 data sources to create a single score.

13 CO-CHAIR PARTRIDGE: Matt, I just want  
14 to warn you, if you want to leave time for  
15 feedback, you're going to lose some of your  
16 audience at noon.

17 DR. WYNIA: Okay, I'll go quickly.

18 CO-CHAIR PARTRIDGE: I don't mean to  
19 ask you to truncate, but I just wanted to warn  
20 you.

21 DR. WYNIA: I got it. I'll skip over  
22 the nine domains and how people are using this



1 for QI, but just to say it is useful for QI.

2 This is nine different sites. Just to give you  
3 an example of the variation in scores both across  
4 sites and within sites, so every site has  
5 something that they don't do as well on as they  
6 would like. The smallest variation is 20 points  
7 which is quite a large variation on these scales.

8 The report, I'll skip through this.

9 This just shows on the lefthand side how we  
10 present the initial data which is to say in this  
11 domain, here's your score, here's the component  
12 that comes from patients. Here's the component  
13 that comes from staff. And on the national  
14 benchmark here's the overall, here's the patient,  
15 here's the staff components. And then we'll  
16 break that out by relevant items from that domain  
17 so that you can see specific item scores and see  
18 whether there's one or two items that are really  
19 dragging down your score.

20 I mentioned already that we  
21 transitioned this to the University of Colorado  
22 earlier this year or late last year, early this

1 year. We've done five assessments in the last  
2 six months. We have a large health system  
3 serving mainly Medicaid populations that is  
4 talking about using this for their DSRIP program,  
5 so this gets to Jennifer's point about starting  
6 to use these types of measures as accountability  
7 and payment-related measures which makes me  
8 extremely nervous as well. And we've actually  
9 got quite a bit of experience using this. But I  
10 just worry about making the patient's responses  
11 to these items super important because there are  
12 so many ways you can game these. This is one of  
13 the reasons why we have consultants working on  
14 this because it's too easy to game these surveys.

15 So these are our future directions and  
16 I'll just drop to the last one for a moment  
17 because it's one of the things I wanted to ask  
18 you guys about. We really encourage the sites to  
19 over sample minority race, ethnicity, and  
20 language populations and so we have a hospital  
21 that used this last -- two months ago and I was  
22 just on the phone with them last week about their

1 disappointment in their scores. And they did an  
2 excellent job of getting non-English language  
3 speaking patients to fill out the survey. And  
4 that's probably why they didn't score as well on  
5 some of these domains. And so they are, in a  
6 sense, being punished for doing a better job of  
7 collecting data from minority patients. And so  
8 we're really struggling with whether we ought to  
9 start doing some kind of risk adjustment for the  
10 patient populations filling out these surveys.

11 I'm very familiar with the NQF's  
12 background in this area of whether and when and  
13 how to use risk adjustment and stratification.  
14 We already stratify. So everyone sees the  
15 stratified data by race, ethnicity, and so on.  
16 But the question is do we also adjust the scores  
17 or back weight the scores in some way to adjust  
18 for the fact that some sites do a better job than  
19 others at recruiting minority patients to  
20 complete these surveys.

21 So I will stop there and look forward  
22 to your questions and comments. And if you don't

1 have questions and comments, I have questions for  
2 you.

3 CO-CHAIR PARTRIDGE: Sam.

4 MEMBER BIERNER: To answer your last  
5 -- I would recommend that you not risk adjust for  
6 those issues because I think those are important  
7 to look at and it's going to vary a lot around  
8 the country. Where I came from, we had a 30 --  
9 50 percent of our patients were -- 30 percent did  
10 not speak English. Fifty percent of them were  
11 Hispanic and that's why with that other measure I  
12 was very concerned because it greatly affects how  
13 some of these questionnaires get answered. So I  
14 would, I think, stratifying where you can see  
15 where it is, but hopefully, there will be a  
16 caveat if some larger organization was using it  
17 for administrative or payment purposes or where  
18 it would cause harm to point that out, that  
19 that's something that needs to be looked at  
20 directly and an area for improvement obviously.

21 CO-CHAIR PARTRIDGE: Way down.

22 MEMBER AVERBECK: Thank you. Beth

1       Averbeck from HealthPartners in the Twin Cities.  
2       Just a couple of comments, one of the -- looks  
3       like the outcome based on the CSAT is around  
4       trust. I'm wondering -- a couple of comments,  
5       wondering have we looked at any kind of quality  
6       outcomes and condition outcomes and maybe because  
7       it's hospital and most of the outcomes are a  
8       process and may not have been correlated as much  
9       with outcomes.

10               As we look to start translating this  
11       into an ambulatory world, the types of care and  
12       the types of interventions switch to some extent,  
13       not necessarily we need to -- obviously, culture  
14       of humility adapt how we're approaching this.  
15       When I look at hospital care, it's around more  
16       rescue care, episodic, acute care. When we look  
17       at ambulatory, we're looking at kind of moving  
18       toward prevention, chronic care management, and  
19       so what I don't know is it the same kind of  
20       correlation, the ambulatory world as we would  
21       find in the hospital world? It's just a question  
22       as you start looking at maybe a broader

1 application of the tool.

2 DR. WYNIA: So I'm hearing two  
3 questions, one of which is what other outcomes  
4 can we look at beyond the outcomes that we did in  
5 the initial validation study. And the second is  
6 what about an application in the ambulatory arena  
7 and are they different, are the outcomes  
8 different there?

9 The initial validation studies were in  
10 18 sites, half of which were ambulatory and half  
11 of which were hospitals. So we intended this to  
12 be used in ambulatory sites to begin with. It  
13 has not ended up being used much in ambulatory  
14 environments, but I think that may change just  
15 because -- and I should say the difference  
16 between a hospital assessment and an ambulatory  
17 assessment is kind of fuzzy sometimes. We've had  
18 sites where an academic medical center uses this  
19 across the whole organization. That's both an  
20 ambulatory site and a clinic site.

21 And so I'm not sure how to tease those  
22 apart, in particular because a patient receiving

1       this may have been both an in-patient and an  
2       outpatient and they are reflecting on their  
3       experience over the last month which may have  
4       been both. So I find it -- I found it  
5       increasingly difficult to say this was an in-  
6       patient assessment versus this was an out-patient  
7       assessment.

8               We do have hospitals that ask -- that  
9       have added an item on the demographics piece to  
10      say at your last visit were you an in-patient or  
11      were you ambulatory so that they can tease apart  
12      the data in that way.

13             On the outcomes question I think there  
14      are so many things that I would love to have been  
15      able to have done with this and we just sort of  
16      lost a bit of a window of opportunity because  
17      just as it was starting to take off, it was sort  
18      of put on hiatus and I feel like in the next year  
19      we -- with a little bit of luck we'll have  
20      another 50 of these by January if we haven't been  
21      contracted.

22             MEMBER AVERBECK: Just our experience

1 in working in this when we looked at the in-  
2 patient, there's less of a gap around the outcome  
3 measure because most of those are process  
4 measures compared to ambulatory, there's more of  
5 a gap in quality in the hospital. There's more of  
6 a gap around some of the experience metrics.  
7 Anyway, just based on some of the -- on the  
8 ground, trying to see what we can do to improve.

9 DR. WYNIA: Very interesting.

10 CO-CHAIR PARTRIDGE: Lisa.

11 MEMBER SUTER: So in the spirit of  
12 trying to give you feedback for when you bring  
13 this back to us, the things that come up for me  
14 thinking through the NQF criteria are in terms of  
15 evidence and performance gap, can you demonstrate  
16 the use of this is associated with improvements  
17 in care. I think that would be given that it's  
18 in use.

19 In terms of scientific acceptability,  
20 you raised a huge issue with the fact that you  
21 acknowledged that it's gameable. So I'd like to  
22 see some evidence for whether or not it gets



1 gamed and how you would address that.

2 In terms of feasibility and usability,  
3 a comment on the burden. It sounds like you  
4 acknowledge that it can only be used through  
5 certified vendors which I assume is a pretty  
6 substantive burden on institutions that are using  
7 this. And I guess the last question is sort of  
8 is this a measure or is this a service? And if  
9 it's a measure, is it one measure, is it nine  
10 measures? How are you presenting those to us  
11 both from a standpoint of evaluating the  
12 evidence. If it's been voted on previously, as  
13 seven or nine different assessments, are they  
14 usable in isolation or is this really intended as  
15 you described as a comprehensive assessment that  
16 really shouldn't be broken apart?

17 I don't quite know what kind of  
18 information to ask you to bring back from that,  
19 but I am struck by the fact that this appears to  
20 be a package as opposed to measure specifications  
21 that could then sort of be put out into the  
22 public domain or are in the public domain. I

1 don't know the C-CAT well and it seems less  
2 similar to some of the other measures that we  
3 voted on today.

4 CO-CHAIR PARTRIDGE: Nicole.

5 MEMBER FRIEDMAN: I wanted to echo  
6 that, too. I was struggling with is this being  
7 program or a service versus a measure. And when  
8 I was looking at this and some of the -- working  
9 with a lot of community-based organizations where  
10 -- that serve a larger non-English speaking  
11 community, low income, uninsured, under insured.  
12 To me, I was looking at this thinking God, this  
13 would be a great thing for a large health  
14 system's community benefit to purchase or to give  
15 on behalf of these social service agencies that  
16 are small and sometimes lack some of these tools  
17 to self-assess. And maybe I was thinking about  
18 it too much in a community benefit form, but I  
19 couldn't see -- it was hard for me to  
20 differentiate the measure versus service. And  
21 that might be a way to avoid looking and  
22 penalizing some of the organizations that yes,

1       they're doing a great job in getting the -- not  
2       the usual suspects that fill out these surveys,  
3       but how do we accelerate that to get more  
4       information. Where to do that where there won't  
5       be that concern.

6               DR. WYNIA: I can say with regard to  
7       measure versus service, I mean it is both, of  
8       course. And the fact that it has the NQF  
9       endorsement makes it a much more valuable, both  
10      measure and service, to organizations. For what  
11      it's worth, people pay attention when NQF says  
12      yes, this measure is worthwhile, spending some  
13      time and energy collecting.

14             I do want to make clear, we don't  
15      require that you use a vendor. Anyone can do  
16      this at any time for free -- anyone who wants can  
17      use these measures. It's just that the reality  
18      is people don't. They've been available for  
19      almost a decade now. And I can't count on one  
20      hand of the number of organizations that have  
21      picked these up off the web or from publications  
22      and contacted me and said we want to do this in

1       our organization and we're very collaborative.  
2       I'd love to see more people doing that. We do  
3       have -- there's a version of this that's being  
4       created for dialysis centers by someone else and  
5       I'm totally supportive of that. So we don't  
6       require people to use vendors, unless they want  
7       their data to go into our benchmarking database  
8       in which case we do require them to work with  
9       someone who's trained and authorized. But if  
10      they want, we will train and authorize someone in  
11      their organization. We'll train a new person,  
12      but the idea is we need to have some assurance on  
13      the quality of the data that are going into our  
14      benchmarking database.

15               Otherwise, -- sorry, the other thing  
16      is on the gaming, just to be clear, any survey is  
17      gameable, right? That's the problem. We're  
18      talking about patient experiences and if we start  
19      making patient experiences super important in  
20      terms of payment, you'll start getting phone  
21      calls from the hospital that sound very much like  
22      the phone calls you get from the auto repair guy

1 where it says if you can't give me a ten on this,  
2 then don't answer the question, right? Because  
3 that's the only thing that matters to us is  
4 getting a ten on this. So these are worthless  
5 data at that point. And it's just a challenge of  
6 using survey data for accountability purposes.  
7 They are all gameable.

8 CO-CHAIR PARTRIDGE: Other suggestions  
9 or comments?

10 Matt, I just have one. I was  
11 interested in your comments about the fact that  
12 in some situations what you probably are  
13 assessing is the entire hospital including its  
14 ambulatory care. And that it's difficult to  
15 tease it apart. And I was taking that back and  
16 thinking well, for now, looking at a set of  
17 performance measures that are derived from this  
18 information, we're probably going to be asking  
19 you to think about teasing that apart or telling  
20 us something about why is it okay to lump them  
21 all together.

22 DR. WYNIA: Yes, this is, I would say

1 the second most frequently asked question by the  
2 organizations using this. And that is what's the  
3 right unit of analysis? I can say that there  
4 isn't one right answer to that because there are  
5 organizations that want to say just give me the  
6 scores for my emergency department or just give  
7 me the scores for the oncology division or give  
8 me the scores -- right? And we've had  
9 organizations that just did the oncology  
10 division. And I think that's perfectly  
11 acceptable.

12 It's also acceptable to do the whole  
13 hospital and recognize that the bigger the unit  
14 of analysis goes, the less sort of detailed value  
15 you get out of that because you know that your  
16 organizational climate is made up of a whole  
17 bunch of microclimates. But that's also true  
18 even within the division of oncology, right? You  
19 will have micro climates where one team is much  
20 better than another team. And so it's a lumpers  
21 splitter problem. There are ways to sort of  
22 frame this, but I don't think there's one right

1 answer.

2 One thing we have done, we have --  
3 when working with the consultants, we have told  
4 organizations we do not recommend and we will not  
5 include your data in the benchmarking database if  
6 you lump together five or six hospitals in one  
7 assessment. That, we know, is so different from  
8 one to the other that we would not -- and I'll  
9 tell you why people want to do this. They want  
10 to do it because it will be cheaper, right, to  
11 work with a consultant to just do one report for  
12 all five of our hospitals and our system, as  
13 opposed to getting five reports.

14 CO-CHAIR PARTRIDGE: But if I were  
15 running that system I would say I think --

16 DR. WYNIA: It's almost useless.

17 CO-CHAIR PARTRIDGE: That's right.

18 DR. WYNIA: That's exactly right. And  
19 that's why we won't facilitate that. I'm not  
20 saying it couldn't happen, because someone could  
21 still do it, but we won't include those data in  
22 the benchmarks and we really strongly discourage

1 people from doing that.

2 CO-CHAIR PARTRIDGE: Becky.

3 MEMBER BRADLEY: You mentioned Joint  
4 Commission and I'm sure you're familiar with  
5 their high reliability organizations. And how  
6 does this compare to what Joint Commission is  
7 doing? Because most large systems use some  
8 accrediting body so as you were describing it, it  
9 sounded like sort of like an accreditation  
10 process to me as opposed to performance measures  
11 that we've typically been --

12 DR. WYNIA: So Paul Schyve was the  
13 chair of our oversight body during the  
14 development of this tool and for those who don't  
15 know, Paul was at the Joint Commission for many  
16 years. And they actually have recommended the  
17 use of this as one means of looking at  
18 communication in the organization and whether  
19 you're meeting their criteria with regard to  
20 language services and with regard to addressing  
21 health literacy in particular. So in their  
22 hospital language and culture report, this was



1 one of the sort of recommended tools for looking  
2 at the organization.

3 The difference is that these are --  
4 you know, we're not using the same methods. We  
5 don't use tracer methods, for example. These are  
6 surveys of patients and of staff asking about  
7 experience of care. So I think these are more  
8 analogous to the CAHPS measures than they are to  
9 a Joint Commission accreditation.

10 Incidentally, one of the questions I  
11 wanted to ask you all is about an effort that we  
12 have in mind to sort of integrate the C-CAT items  
13 and the CAHPS items. We went through some  
14 rigmarole with CMS early on to make sure that it  
15 was okay for organizations to use the C-CAT  
16 patient survey because you may know that if  
17 you're doing the CAHPS surveys, which everyone  
18 is, you can't do other surveys that look similar.  
19 And so we had to change some of the items. This  
20 was before NQF endorsement. We had to change  
21 some of the items in order to make sure that we  
22 were not stepping on the toes of the CAHPS

1 survey.

2 And one of the thoughts we've had is  
3 we might be able to do a shorter patient survey  
4 than we've got right now if at this time everyone  
5 has CAHPS data and we could bring the data in  
6 from specific items of the CAHPS survey and use  
7 those instead of some of the items we have on our  
8 survey and still be able to calculate the domain  
9 score. That gets even more complicated now  
10 because now we're looking at a response rate for  
11 our survey, a response rate for CAHPS, different  
12 people responding, right, and trying to -- so it  
13 feels like a mess to me statistically and in  
14 terms of reliability and so on.

15 On the other hand, anything to make it  
16 easier for people to actually use, you know,  
17 makes it easier for people to actually use.  
18 Thoughts on that?

19 MEMBER MELILLO: Yes. I was just  
20 wondering if you've tested or intend to test it  
21 in other in-patient settings, so post-acute.

22 DR. WYNIA: Yes, it's been used in a

1 variety of settings at this point. So we started  
2 with this set of testing sites that were half  
3 clinics and half hospitals, but subsequently  
4 we've had specific units within hospitals do it  
5 and we've had entire hospitals do it. It's been  
6 mostly that though. It's been either a unit  
7 within a hospital, so like the department of  
8 medicine or the intensive care units in a  
9 hospital.

10 MEMBER MELILLO: So I was thinking  
11 more along the lines of an in-patient  
12 rehabilitation facility.

13 DR. WYNIA: An LTAC, yes.

14 MEMBER MELILLO: Yes.

15 DR. WYNIA: I would relish the  
16 opportunity to work with LTACs or any amount of  
17 SNFs, I'll work with anyone.

18 MEMBER MELILLO: Okay.

19 DR. WYNIA: I think it's -- you can  
20 pull up the survey. The items are pretty  
21 generic, so these are items about effective  
22 communication, which is going to be relatively

1 similar across multiple types of organizations.

2 MEMBER AVERBECK: How many languages  
3 do you have available for the patient component  
4 of the survey?

5 DR. WYNIA: That's a really good  
6 question. I think we're on the order of 12 or  
7 17. And we'll do additional languages if an  
8 organization needs that language. We have a  
9 vendor that we use that works --- incidentally,  
10 our language translation service will then work  
11 with the organization to develop the new language  
12 because there are regional differences across the  
13 country and so we want to make sure that they do  
14 not just sort of a language -- forward translate,  
15 back translate kind of thing. They need to  
16 actually do a little bit of pilot testing in the  
17 local community to make sure the items make  
18 sense.

19 MEMBER AVERBECK: Thank you.

20 CO-CHAIR PARTRIDGE: Peter.

21 MEMBER THOMAS: I'm just curious  
22 following up on that point. Effective

1 communication is a really important concept in  
2 disability law and do you make accommodations for  
3 vision impaired, speaking impaired, hearing  
4 impaired?

5 DR. WYNIA: Yes, that's an excellent  
6 question. And we have items on the survey about  
7 that actually, about the availability of hearing  
8 aids and so on within a hospital setting, for  
9 example, and glasses within a hospital setting.  
10 And what we -- we've tried a couple different  
11 things that have not been really successful, so  
12 we had for a while, and we still have this, but  
13 we just don't use it. We have an iPad version of  
14 the survey where the survey is read to you by the  
15 iPad in a couple of different languages, I think  
16 three different languages.

17 And we have some -- we've tried to  
18 make the survey as easy as possible. It does not  
19 have any compound phrasing, unlike the CAHPS.  
20 The issues around visually impaired are difficult  
21 because the only way we've really got to deal  
22 with that right now is a staff person can read

1 the survey to you and help you fill it out. And  
2 if so, they are supposed to check a box on the  
3 front of the survey to say a staff person helped  
4 fill out the survey. So -- because I worry about  
5 staff helping people fill out surveys for obvious  
6 reasons. But that's how we deal with it right  
7 now. We spent \$10,000 on that iPad version and  
8 no one ever used it. That was eight years ago,  
9 seven years ago. It was the first version of the  
10 iPad. So it may be that if we were to reinitiate  
11 that now, it would be easier because iPads are  
12 ubiquitous in hospitals. They were not at that  
13 time.

14 CO-CHAIR STILLE: They're also a lot  
15 more reliable, just having done some iPad surveys  
16 in our clinical realm with security things and  
17 stuff like that. They work. They didn't use to.  
18 And I suspect they would be more accepted.

19 DR. WYNIA: Right, I just want to  
20 note that Sherrie Kaplan has not asked me a  
21 single question and I'm feeling a little  
22 neglected.

1 (Laughter.)

2 MEMBER KAPLAN: I have been so good --  
3 all right, I have one question, one quick one  
4 because it's time. NIH now is moving towards,  
5 they're very nervous about quality improvement  
6 activities that are shading over into requiring  
7 informed consent. And so because ethics, as you  
8 know, is not my field, we just published in  
9 American Journal of Bioethics. We asked  
10 patients, would you like to be informed about and  
11 get consent from different kinds of quality  
12 improvement activities? And it turns out the  
13 patients are very nervous about sharing their  
14 data and other things that hospitals are  
15 routinely doing now without their permission.

16 Have you thought about and in light of  
17 our prior shared decision making thing, have you  
18 thought about adding a dimension here? I know  
19 how standardization works and I wouldn't worry  
20 that benchmarking is an issue, but sort of the  
21 whole informed consent and shared decision making  
22 issue. Have you thought of adding a little --

1 some stuff in your various different measures  
2 that cover that domain? Because this is now  
3 beginning to be a little bit dated in terms of  
4 its content?

5 DR. WYNIA: Yes, so we have items on  
6 shared decision making about were you involved in  
7 the decision? Did people ask for your opinion?  
8 Did they respect your opinion, those kinds of  
9 items. Did they include you in decision making?

10 We do not have items about how do you  
11 feel about sharing your data, using your data in  
12 research or quality improvement work. I was on  
13 this Hastings Center group a few years back where  
14 we actually came down to say this an ethical,  
15 moral responsibility on the part, not only of the  
16 organization, but of the patients who come there  
17 to allow their data to be used in these ways to  
18 improve the quality of care because after all,  
19 you're benefitting from the improvements in  
20 quality of care. That was not without some  
21 controversy, but the idea was, with the right  
22 safeguards in place, everyone should allow their



1 information to be used and part of that is driven  
2 by the pragmatics of the situation which is it's  
3 essentially impossible to segregate out one  
4 patient's data when they're doing the QI project  
5 in the ICU, and not use just those data because  
6 they ask to keep all their stuff private. It's  
7 very difficult.

8 But anyways, it feels to me like that  
9 issue would be a separate set of issues and it  
10 would be -- they're an interesting set of issues  
11 and I know the survey data on this suggests that  
12 patients are a lot more reticent -- depending on  
13 how you frame the question. They're more  
14 reticent to share their information than we would  
15 like them to be and probably for reasons that are  
16 legitimate.

17 CO-CHAIR PARTRIDGE: Matt, thank you.  
18 I hope this is helpful to you and your team.

19 DR. WYNIA: Yes.

20 CO-CHAIR PARTRIDGE: It's certainly  
21 been informative for us.

22 DR. WYNIA: Thanks.

1 CO-CHAIR PARTRIDGE: So we'll look to  
2 seeing you back here.

3 DR. WYNIA: Yes, we'll keep working  
4 with Sarah until we get it right and then we'll  
5 bring it back.

6 CO-CHAIR PARTRIDGE: Break for lunch  
7 and then Karen is going to join us, talk a little  
8 bit about hospice and it's up to the rest of you  
9 all.

10 MS. SAMPSEL: What we'll do is if  
11 everybody will go ahead and grab lunch and take a  
12 quick break. Karen Johnson is going to come in.  
13 Karen is one of my colleague senior directors and  
14 basically, we'll introduce it more, but one of  
15 the CAHPS surveys went through a different panel.  
16 We're spreading the wealth on some of these fun  
17 measures and so Karen just wanted to get some  
18 feedback from this group because it has not all  
19 gone through the process yet and then for those  
20 folks who can stay around, we still need to have  
21 kind of a gaps discussion a little bit later.

22 MEMBER THOMAS: Can I ask a question?

1 Can we also put on the agenda after lunch if  
2 anyone has any comments on any of the measures we  
3 looked at yesterday, second thoughts, or just  
4 kind of comments that we might want to revisit?

5 MS. SAMPSEL: Sure. I guess what I  
6 should have mentioned there, too, is depending on  
7 how many people we have hanging out, I think  
8 there are still, and we'd love to get some  
9 additional feedback on kind of pushing the field  
10 forward on testing as well, which goes into some  
11 of those comments and some of the things that  
12 Sherrie brought up yesterday. So I think that  
13 would work out quite well.

14 (Whereupon, the above-entitled matter  
15 went off the record at 12:06 p.m. and resumed at  
16 12:24 p.m.)

17 MS. SAMPSEL: So, I think I can  
18 actually get started while Kirsten's bringing up  
19 the slides. But, basically, we have joining us,  
20 Karen Johnson, who is one of my peer senior  
21 directors.

22 And Karen was managing the Palliative

1 and End of Life Care Standing Committee that met  
2 a few weeks ago. And as I mentioned before  
3 break, we've started spreading the wealth a  
4 little bit about -- on some of the CAHPS  
5 measures, some of the experience of care  
6 measures, quality of life measures, et cetera.

7 And putting them into their intended  
8 focus areas versus bringing everything to person  
9 and family centered care. Part of that is the  
10 result of the growing portfolio in person and  
11 family centered care.

12 And just the fact that we're keeping  
13 you guys really busy. Which, you know, it's  
14 good. It's good job security for me.

15 But, we think that there are sometimes  
16 where some of these measures could really use  
17 some input. And perhaps the recommendations from  
18 a specialized committee.

19 So, in starting that transition, one  
20 of the first areas was hospice palliative  
21 care/end of life care, where Karen's group not  
22 only did the hospice CAHPS measures, but also

1       some pain measures. And dealt with some of the  
2       same issues that we dealt with yesterday.

3               But, what -- our intent here then is  
4       to create an excuse of information between the  
5       committees. And make sure that, you know, the  
6       hospice and palliative care -- or the palliative  
7       care and end of life committee benefits from some  
8       of the input you all may have given.

9               Because you've looked at numerous  
10       CAHPS and experience of care types measures. As  
11       well as in the event that if there was another  
12       committee looking at something that, you know,  
13       just want some of the broader survey or tool-  
14       based measure input, we can provide that.

15              To the same degree, there may be  
16       measures that were originally slated to come to  
17       this committee, such as there's a renal or  
18       dialysis quality of life survey. There are some  
19       other surveys that we've started to move into the  
20       other portfolios, but we still want to make sure  
21       there's an exchange of information.

22              So, -- and this is for consistency

1 purposes. But also just really that specialized  
2 expertise purposes.

3 So, that's what we're looking for  
4 here.

5 MS. JOHNSON: So, thank you, Sarah.  
6 And if you could just go to the next slide,  
7 please.

8 I will point out that not only is our  
9 Palliative Care Committee learning about these  
10 kinds of measures, but also I am as well. So  
11 this will be the first time I have shepherded one  
12 of these kind of measures through.

13 I'll give a lot of kudos to the CMS  
14 folks who filled out their forms. Because they  
15 did an excellent job. They made it pretty easy  
16 for us to understand what was going on with the  
17 various CAHPS measures.

18 So, I'm just going to walk you through  
19 very quickly what the measures were. Give you a  
20 little bit of the data that they provided. And  
21 then we'll open it up to any discussion and  
22 feedback you may want to give.

1                   So, first of all, there were eight  
2       PRO-PMs included in this measure. And I know you  
3       guys are familiar with the CAHPS methodology.  
4       And they used the same scoring methodology, this  
5       top-box scoring that the other CAHPS surveys tend  
6       to do.

7                   So, they had six measures taken from  
8       multiple items, as well as two measures from  
9       single items. Those global rating measures. And  
10      you can see on this screen, I'm not going to read  
11      all of these out to you. But, you can see that  
12      there were different numbers of items going into  
13      each of these different domains if you will.

14                  Any questions about this? I should  
15      mention a couple of extra things. This is, of  
16      course, a survey that is fielded to the family  
17      member, or really, the primary care giver of  
18      hospice decedents. It's fielded about a couple  
19      of months after the death of the patient in the  
20      hospice. And it is a facility level of analysis.

21                  I think that's the main things. The  
22      developer, it was kind of interesting, they talk

1 about several exclusions to the measure. But,  
2 when we really did a deep dive on this, they  
3 really weren't exclusions to the various  
4 measures. They were really things that kept the  
5 family from getting the survey in the first  
6 place. They were never really in the  
7 denominator. And question?

8 MEMBER BEVANS: Yes, just a quick  
9 question. The scoring of the measures, is it --  
10 if it's top-box scoring, but there are multiple  
11 items that go into each of the -- so, is it the  
12 percent of top-box endorsement?

13 Let's say on the six items that make  
14 up hospice, team, communication, how does that  
15 work? Or is it each individual item stands  
16 alone?

17 MS. JOHNSON: Each individual item  
18 doesn't stand alone. And I didn't write down the  
19 actual scoring methodology.

20 Let's see, items of never, sometimes,  
21 usually, always, is the top-box score. And they  
22 -- golly, I wish I could remember exactly what



1       they do.

2                   I think they average it across the  
3       four items. And go from there. They did a  
4       really nice job of giving us an example of how  
5       you calculate it.

6                   And my apologies for not remembering  
7       that. I can provide that to you if you want to  
8       know.

9                   Any other questions?

10                  (No response.)

11                  MS. JOHNSON: Okay. Let's go to the  
12       next slide, please? So, just a few more details  
13       about the survey methodology.

14                  As I mentioned, the population is  
15       primary care givers of hospice decedents. The  
16       measures are all adjusted for mode of  
17       administrative, as well as case mix.

18                  And for mode of administration, for  
19       these measures, or the survey can be done mail  
20       only, telephone only, or some kind of mixed way.  
21       And part of the trick there is the individual  
22       agency can decide which way they want to do that.

1           But, mail is cheaper than the other  
2 forms. So, there was a little bit of difference.  
3 And that's why they needed to adjust for mode.

4           They do allow sampling for agencies  
5 with more than 700 decedent care giver pairs per  
6 year. And also, it -- you may or may not know,  
7 this survey is already included in the CMS  
8 Hospice Quality Reporting Program.

9           So, hospices are already reporting.  
10 And right now, they have, in about, I think they  
11 really have only been doing this for about a  
12 year.

13           They only have two quarters worth of  
14 data right now. But they have data, so far, on  
15 about 70 percent of the survey eligible hospice  
16 agencies.

17           So, it's important to note that  
18 hospices with fewer than 50 decedents per year  
19 are not required to field the survey. So, that's  
20 one way that they work on their small sample  
21 size.

22           And as with the other CAHPS surveys,

1 they must be fielded by a vendor. So, any  
2 question about the survey itself?

3 (No response.)

4 MS. JOHNSON: Okay. Let's go to the  
5 next slide. So --

6 CO-CHAIR PARTRIDGE: Just --

7 MS. JOHNSON: Yes?

8 CO-CHAIR PARTRIDGE: Karen, just one  
9 thing. I'm thinking back, and I was quizzing  
10 Sarah too.

11 And as I remember, we had a brief  
12 discussion with CMS about both -- were they  
13 asking us to recommend endorsement of the scoring  
14 methodology, i.e., top-box, and mode of  
15 administration, as well as the measures that were  
16 before us. But, were they asking us to endorse  
17 how the survey itself was administered, and we  
18 explicitly didn't.

19 MS. JOHNSON: Right.

20 CO-CHAIR PARTRIDGE: I just --

21 MS. JOHNSON: Right. And when we're  
22 writing this up, we definitely are trying to over

1 and over and over repeat that there are eight  
2 PRO-PMs out of this one number, 2651.

3 So, all this stuff is interesting  
4 because it impacts how the measures are  
5 calculated. You know, the adjustment, et cetera.

6 But, we are not endorsing the CAHPS  
7 survey or its methodology. You're absolutely  
8 correct.

9 Just to show you here, and I did  
10 listen in a little bit to some of your discussion  
11 yesterday. And that gave me a little bit of  
12 reason to put a couple of these things on the  
13 slides.

14 But, I wanted to show you where we are  
15 in terms of performance. And this is just one  
16 quarter's worth of data that they had available.

17 But, you can see here that the scores  
18 are pretty high. But, they're not topped out  
19 yet, which is encouraging.

20 I will tell you one of the things that  
21 was somewhat encouraging to me with the  
22 palliative care project. Several of the other

1 measures that are used in the Hospice Quality  
2 Program for CMS, I had actually never seen the  
3 results of those.

4 They're not published yet. They're  
5 not, you know, publically reported. And many of  
6 those are getting close to being topped out  
7 already.

8 So, it was kind of good to see that,  
9 in an odd way, kind of good to see that there's  
10 still opportunity for improvement for these  
11 measures. So, not only are the means, you know,  
12 not quite yet topped out.

13 But there's also quite a bit of  
14 variation across the percentiles there that you  
15 can see.

16 CO-CHAIR STILLE: Just a quick -- oh,  
17 sorry, Sherrie first and then I'll.

18 MEMBER KAPLAN: Karen, I'm kind of  
19 shocked that they didn't -- because getting help  
20 for symptoms is one of their lowest scores.

21 And I'm shocked that they didn't do  
22 pain management. Because that's one of the

1 HCAHPS measures. And it's one of the big drivers  
2 of the overall rating.

3 I'm really surprised that they didn't  
4 put that in there, you know. It -- again, it's  
5 one of the -- it's both -- effective pain  
6 management is one of the big drivers of overall  
7 rating and recommendations of the care to the  
8 hospital to others from HCAHPS.

9 So, what will -- did they give a  
10 rationale for doing that?

11 MS. JOHNSON: They didn't. Although,  
12 and I should have had this up. And I apologize  
13 for not having it up. Let me see if I can find  
14 it quickly.

15 What I don't know is the help for  
16 symptoms. If the pain question was in there.  
17 And I can find that out for you, very quickly if  
18 you want to give me just a second.

19 Sorry, I had no idea what you guys  
20 were going to ask. So, I didn't do a very good  
21 job of guessing.

22 So, symptoms. Did your family get as

1 much help with pain as he or she needed? How  
2 often did your family member get the help he or  
3 she needed for trouble breathing, for trouble  
4 with constipation, and for feelings of anxiety or  
5 sadness?

6 So, that is the three major symptoms  
7 on the hospice. So, that's what they did. Great  
8 question.

9 CO-CHAIR STILLE: And now I just had  
10 a little point about, you know, when they do all  
11 top-box scoring, and your having means, you know,  
12 over 80 percent, that means that 80 percent have  
13 the highest rating.

14 And I wonder sometimes, you know, the  
15 higher you get, when's sort of the cut off for,  
16 you know, clinical, meaningful medicine? And for  
17 me it would be if it gets better with  
18 intervention.

19 You know, it has the potential to even  
20 get better with intervention. And then I start  
21 to wonder, you know, when they get really -- the  
22 scores get really high.

1                   So, you know, any evidence about  
2                   whether there's, you know, improvement projects  
3                   that are working on that, or something like that.  
4                   Combined with knowing exactly how they calculated  
5                   the measure, I think would be helpful.

6                   MS. JOHNSON: I will say that at least  
7                   a couple of people on the palliative care  
8                   committee, were a little bit -- they weren't a  
9                   fan of that top-box scoring. They really thought  
10                  it was too high a bar.

11                  And you know, so you weigh that with  
12                  a, you know, is it too hard versus, well, we're  
13                  looking for great. Right?

14                  CO-CHAIR STILLE: And I guess what I'm  
15                  thinking is, it's not too hard if you can do  
16                  something to make it better.

17                  MS. JOHNSON: Yes.

18                  CO-CHAIR STILLE: If you can't do  
19                  anything to make it better, then it's getting to  
20                  be too hard.

21                  MS. JOHNSON: Yes. Yes. And you  
22                  know, it's tricky because it's so new. We don't



1 know if those numbers are going to go up or not.

2 Again, so many of the other measures  
3 that are used in the hospice program right now of  
4 the CMS, as I said, some of them are already at  
5 the 95 percent. You know, the screening for  
6 pain, the screening for dyspnea. All those  
7 things.

8 You know, they're quite -- they're not  
9 very exciting measures. You know, I have to say  
10 that these are the -- probably some of the more  
11 exciting things that we had to talk about in our  
12 committee.

13 And that may be a good or bad thing.  
14 I mean, anecdotally they were saying that  
15 hospices had actually, you know, even though  
16 we're just now seeing data, you know, at this  
17 point in time, five years ago when some of them  
18 were first starting, the numbers weren't nearly  
19 so good.

20 So, there actually has been  
21 improvement. Even though, you know, at our point  
22 in time, we're not seeing it.

1 All right, Jennifer?

2 MEMBER BRIGHT: Forgive me, because  
3 this may be a late question. But I just want to  
4 understand who's in this data set?

5 Is this only for inpatient hospice?  
6 Or is this also reflecting delivery of hospice in  
7 the home? Or in -- like in the long term care  
8 facility where hospice services are brought in?

9 MS. JOHNSON: Right. It would be any  
10 hospice admission. So, hospice is primarily, as  
11 you know, provided in the home. I think it's  
12 somewhere around 90, 95 percent of hospice care  
13 is provided in the home.

14 So, it doesn't have to be inpatient.

15 MEMBER BRIGHT: Right. I just wanted  
16 to know is that all brought together?

17 MS. JOHNSON: Yes. It's everybody.  
18 Yes. And it's everybody, and there again, I  
19 mentioned that whole list of exclusions.

20 But, obviously if the hospice patient  
21 didn't die, they're not given, you know, their  
22 family isn't given the survey. And that's a big

1 chunk of hospice enrollees, right?

2 A lot of people are discharged alive.  
3 They don't have decedents less than 18. I'm not  
4 quite sure what the thinking of that really is.

5 I think that -- I don't know if that's  
6 a CAHPS usual thing or not. Yes, I'm not sure  
7 why.

8 If the decedent had no caregiver of  
9 record, then they can't fill the survey. Or if  
10 the caregiver said, don't give me the survey,  
11 then they didn't do it.

12 So, there's those kinds of things that  
13 are -- exclude some of those. And that's why I  
14 put up that sampling is allowable if you have  
15 more than 700 decedent/care giver pairs, if you  
16 will.

17 Any other questions before we go to  
18 the next one? Sherrie, you'll enjoy the next  
19 slide. Let's look at reliability.

20 So, this is what they gave us. So,  
21 they did give us our data element information.  
22 So, how did the instrument itself do using

1 Cronbach's alpha and then the item total  
2 correlations.

3 And then at the score level for each  
4 of the PRO-PMs, they gave us the ICCs. And then  
5 did an estimated reliability, assuming that the  
6 sample size was 200.

7 And that of course engendered some  
8 discussion. Those reliability estimates are, you  
9 know, they're not bad. They're maybe not as high  
10 as we might like to see.

11 Maybe the thing that was a little bit  
12 more iffy was the fact that they did it for n  
13 equals 200. So, lots of agencies have more than  
14 200 in a year. Right? But, a lot don't. So,  
15 there's going to be potentially a small sample  
16 effect there.

17 MEMBER KAPLAN: Okay so I'm confused.

18 MS. JOHNSON: Okay.

19 MEMBER KAPLAN: Say it's score -- what  
20 does score level mean? Because what we are  
21 looking for with these measures that are being  
22 used at the facility level, is more between

1 facility variance then within facility variance.

2 So, at the patient level, it can be  
3 reliable. That's, I think that's what they're  
4 saying data element level is.

5 MS. JOHNSON: Yes.

6 MEMBER KAPLAN: -- is Cronbach's  
7 alpha. That's the right internal consistency.  
8 Reliability is what you'd look for.

9 MS. JOHNSON: Right.

10 MEMBER KAPLAN: Is the patient giving  
11 you consistent responses across the questions.  
12 But, at the facility level, what you're looking  
13 for, is there more between physician variation  
14 than within physician variation?

15 So, if there's a lot of within  
16 physician variability, that's trouble at the  
17 facility level in terms of reliability. Because  
18 then you get a lot of noise.

19 There is no facility thumbprint across  
20 patients in that facility. And that's what it  
21 looks like the ICC is telling you.

22 And Helen, that's kind of a problem.

1       Should this be -- is this reliable at the  
2       facility level?

3               And if that's what that column is  
4       telling you, the third one over, it's not. So --

5               MS. JOHNSON: So --

6               MEMBER KAPLAN: And I don't get what  
7       estimated reliability for n equals 200 per  
8       facility. That's not going to bump the  
9       reliability, the ICCs up that much.

10              MS. JOHNSON: Right. So, I'm just  
11      going over my notes here. Let's see. They -- I  
12      don't have major notes on what they did for their  
13      ICCs and how they did this.

14              They did use the Spearman-Brown  
15      prophecy formula. So, basically what I have here  
16      in my notes, they estimated the reliability using  
17      Spearman-Brown prophecy formula, assuming 200  
18      surveys were completed in each agency.

19              MEMBER KAPLAN: But that's what they  
20      used for -- that -- it doesn't help you enough if  
21      they're using 200 per facility.

22              And they're using the -- they're not

1 using some level of testing for is there more  
2 between versus within facility variability.

3 MS. JOHNSON: Yes. So, let me read  
4 you what they said.

5 Inter-unit reliability. Yes, they're  
6 not giving us much more than what I've already  
7 told you.

8 And just so you know, Sherrie and I  
9 have talked about this a lot. And I'm still  
10 trying to learn. I don't -- I completely agree  
11 that they should be giving us the between  
12 compared to within variation. I believe that's  
13 what they think they've done.

14 MEMBER KAPLAN: I think they did that  
15 in the third column. Then the question is, is it  
16 reliable at the facility level? See, these  
17 measures are great at the patient level. They've  
18 all been tested at that level over, and over, and  
19 over.

20 MS. JOHNSON: Right. Right.

21 MEMBER KAPLAN: We don't need to do a  
22 lot of that kind of testing any more with these

1 kinds of measures. Except in a new application  
2 like this.

3 But, when you're -- if you're going to  
4 use them to compare facilities, you want the  
5 sense that gee, yes, there is a lot more between  
6 facility variance than within facility variance.  
7 Otherwise, it's great at the patient level. But,  
8 it doesn't -- it's not very good as a quality  
9 measure of the facility's performance. So, it's  
10 not very reliable.

11 MS. JOHNSON: So, when you're looking  
12 at these ICCs, Sherrie, you would interpret this  
13 as, that top one for example, 1.3 percent of the  
14 variation is between facilities. Is that how you  
15 would -- that's how you would actually interpret  
16 that number?

17 MEMBER KAPLAN: See a big number there  
18 is .7.

19 MS. JOHNSON: Right.

20 MEMBER KAPLAN: That means that  
21 there's a lot more -- the score goes up because  
22 the numerator is the between facility variance.



1 The denominator is the between plus within  
2 facility variance.

3 MS. JOHNSON: Right.

4 MEMBER KAPLAN: So, as the within  
5 facility variance goes up, the ICC goes down.  
6 So, what you would see, if there's very little  
7 between facility variance, and there's a lot of  
8 within facility variance, that would give you a  
9 low ICC.

10 And that's what it looks like is going  
11 on here.

12 MS. JOHNSON: so, in terms of them  
13 giving the estimate, and apologies, I'm getting a  
14 tutorial here, kind of ahead of the game.

15 DR. BURSTIN: Yes. We can take this  
16 up offline.

17 MS. JOHNSON: Yes. We probably do  
18 need to.

19 CO-CHAIR STILLE: I actually think we  
20 all are getting one.

21 MS. JOHNSON: So, turning the ICC into  
22 the estimated reliability with the particular

1 sample size, you don't find that helpful?

2 Because the committee was looking at  
3 that final, you know, when they were making their  
4 decisions about recommendations for endorsement  
5 or not, they were really looking at that  
6 estimated reliability number. That final column,  
7 not the third one.

8 MEMBER KAPLAN: Spearman-Brown  
9 prophecy formula tells you how many variables of  
10 what -- and with what magnitude of association,  
11 plus how many pay -- how many subjects you need  
12 to sample that number of measures on with that  
13 level of association with each other.

14 So, if a -- measures are all  
15 associated, say, at the level of they're like  
16 correlated at .3, say on a, you know, zero to one  
17 scale.

18 So, they're correlated at .3. How  
19 many of those measures do you need? And how many  
20 subjects per measure do you need to get a stable  
21 estimate of whatever you're looking at's  
22 performance?

1           The problem is, I don't know what they  
2       did with that final column. I can't -- I don't  
3       know what they used in the estimate to get that  
4       number.

5           It would really be bizarre to go from  
6       whatever it is that was used to estimate the  
7       third column, which I suspect -- they said they  
8       had like -- they're at least have a sampling of  
9       at least 50, right?

10           MS. JOHNSON: Right.

11           MEMBER KAPLAN: And the average number  
12       of subjects per whatever was about 200 -- I  
13       thought it was about 200.

14           So, it's really weird to see what's  
15       going on. The two columns don't make sense to  
16       me.

17           MS. JOHNSON: Okay. So that's  
18       something I'll go back to them and ask them to  
19       explain for us. That's very helpful.

20           Any other questions about this? We're  
21       kind of at the max of my understanding of ICCs  
22       and reliabilities at this point.

1           Let's go to the next one. Let me tell  
2 you a little bit about what they did for  
3 reliability testing.

4           Basically, and this is probably not  
5 unusual for you guys to see. They did some  
6 linear regressions with the six multi-item PRO-  
7 PMs. So, basically they just regressed those  
8 onto the two global PRO-PMs.

9           And the relationships were  
10 statistically significant and decent affect size.  
11 And it confirmed our hypothesis of a positive  
12 relationship.

13           They also looked at Pearson  
14 correlations between the six multi-item PRO-PMs.  
15 The correlations were moderate to large, which is  
16 what they expected.

17           So, from that, they inferred that the  
18 different measures reflect what they call unique  
19 but related constructs. And between the two of  
20 these things they and the committee actually felt  
21 that they had demonstrated that the measures are  
22 valid.

1                   MEMBER SUTER: Hi Karen. Did they  
2 look at either face validity with patients, care  
3 givers, providers? Or, you know, any -- or  
4 associations with other assessments of hospice  
5 quality?

6                   Some of the other measures, whether  
7 they, you know, more than three days enrollment  
8 before your death? You know, other symptom  
9 control outside of the domains that they were  
10 assessing?

11                  MS. JOHNSON: Right. They did in  
12 terms of demonstrating that the items and the  
13 topics were important to caregivers of hospice  
14 patients.

15                  They did several focus groups and  
16 individual interviews to talk to them. And the  
17 results suggested that they find these -- the  
18 topic items, communication information, respect,  
19 et cetera, to be important facets of high quality  
20 hospice care.

21                  So, I think they did demonstrate that  
22 the respondents would find these questions

1 meaningful. So, they did that and the committee  
2 didn't have any concerns about that.

3 In terms of did they match it up or do  
4 any other analytics to go with the other  
5 measures, they didn't talk about doing any of  
6 those things. If they did them, they didn't  
7 mention them.

8 So, and I'm trying to remember your  
9 idea about the three days is an interesting one.  
10 And I don't -- let me look at my exclusion list  
11 just to make sure.

12 They actually don't include decedents  
13 who died within 48 hours of admission. So, those  
14 really short stays are not included in the  
15 measure.

16 So, that -- and you know, that is kind  
17 of limiting the measure. There are a lot of  
18 folks who are in hospice for not enough time,  
19 right? But, that is one of the exclusions. That  
20 might be one of the things that if they did look  
21 at shorter stays, they didn't report those. But,  
22 the very short stays are not even included.

1 Sherrie?

2 MEMBER KAPLAN: Can I ask, Karen, did  
3 they go beyond the survey? Because the first,  
4 you know, when you correlate these multi-item  
5 measures that scales with the two global item  
6 measures, you're doing construct validity, but  
7 you're within the survey document itself.

8 MS. JOHNSON: Right.

9 MEMBER KAPLAN: Did they go beyond the  
10 survey document to try and associate its -- these  
11 measures with other things we know about the  
12 hospice facilities, or no?

13 MS. JOHNSON: No. No, they didn't.  
14 They only did it within the survey.

15 MEMBER KAPLAN: Because it kind of --  
16 where are they in the development of this thing?  
17 Because if -- this is kind of step one.

18 You want to make sure that the  
19 information you're getting from the sub-scales is  
20 associated with a validity variable within the  
21 survey. Like overall rating, or behavioral  
22 intentions.

1 MS. JOHNSON: Right.

2 MEMBER KAPLAN: But then you want to  
3 go beyond the survey, because you get these  
4 methods effect. You know, people are going to  
5 give you the same answer within the same data  
6 collection method, in this case, the survey.

7 If you go beyond that method of data  
8 collection, then that's where you really get some  
9 sense that this is giving you something that's  
10 interpretable.

11 MS. JOHNSON: Right. So, if they did  
12 it, they didn't report any of those analyses to  
13 us. And I'm about 99 percent sure that they  
14 didn't. And I will apologize if they did and I  
15 forgot. If it came up during the conversation.  
16 I don't think they did.

17 As to how far along this is, it is  
18 fully baked. I mean, hospices are reporting.  
19 You know, they are fielding these surveys and  
20 reporting on these right now. They didn't  
21 mention really what they would be doing in terms  
22 of updating things as they went along. They are



1 working, I think they recalibrate some of their  
2 risk adjustment models as time, you know, they do  
3 that every so often.

4 But I think that's the only thing that  
5 they mentioned so far in how they're doing that.  
6 And again, I'm trying to think, I mean, right now  
7 there's only, besides the CAHPS measures, there's  
8 only seven other measures that are being reported  
9 across hospices, at least to CMS. So, across the  
10 board. And those are the ones that I pretty much  
11 already mentioned. Are you screening for pain?  
12 Are you assessing for pain? Are you screening  
13 for dyspnea? Are you treating dyspnea?

14 Let me think. I've got only five  
15 minutes, so I better hurry. There's a couple of  
16 more that have to do with bowel regimen and  
17 spiritual beliefs.

18 So, they're all pretty basic measures  
19 that are pretty much assessed at hospice  
20 admission. So, there's not a whole lot there  
21 that they can do, again, across the board.

22 They could do it in a more researchy

1 kind of way with a smaller sample I would think.  
2 But, not with the data that they have in house  
3 for all hospices.

4 Let's go to the final slide. What  
5 happened with the committee? You guys definitely  
6 asked some questions that our committee didn't.

7 At the end of the day, our committee  
8 was concerned with two of the measures. The  
9 treating family member with respect and the  
10 getting help for symptoms.

11 Those were the ones that had the  
12 lowest estimated reliability number that N equals  
13 200. So, they pulled those out for separating  
14 voting for reliability.

15 Not for any of the other things.  
16 Evidence was the same. Gap was close enough they  
17 didn't feel like separating them out there, et  
18 cetera.

19 With the treating the family member  
20 with respect, they did not reach consensus on  
21 that one. Everything else they did.

22 So, therefore seven of the eight were

1 recommended for endorsement. That eighth one,  
2 treating family members with respect, we will  
3 revisit that after post-comment. And they'll  
4 have a chance to vote at that point.

5 MEMBER MELILLO: So, I maybe showing  
6 my statistics weakness as well from grad school,  
7 but did they do an item if deleted analysis? Is  
8 that the right terminology for the --

9 MEMBER KAPLAN: What happens to the  
10 Cronbach's alpha if the items' deleted from the  
11 scale?

12 MEMBER MELILLO: Yes.

13 MEMBER KAPLAN: They took a select  
14 number of --

15 MEMBER MELILLO: To select them.

16 MEMBER KAPLAN: With that number of  
17 small, they got some of these are two and three.  
18 So, you probably wouldn't --

19 MEMBER MELILLO: Yes.

20 MEMBER KAPLAN: Except for the one  
21 with six items, you probably wouldn't expect them  
22 to do that.

1 MS. JOHNSON: And again, you know, I  
2 got the impression from listening to them that  
3 they did a lot of analysis. They didn't show us  
4 everything they did.

5 And that's, you know, not necessarily  
6 one of the things that we asked for. So, if they  
7 did it, they didn't report that under submission.

8 A couple of other things that came up,  
9 I think, from our committee, is there was a  
10 little bit of discomfort actually in the --  
11 Kirsten, can you go back to that very first slide  
12 where I show you the -- that second slide, sorry.

13 The emotional and religious support  
14 measure with the three items, some folks thought  
15 that that was odd that those tracked together.  
16 They really thought emotional should be different  
17 then spiritual or religious.

18 Their Cronbach's alpha apparently  
19 supported putting those together. But, that was  
20 something that kind of raised flags with our  
21 committee.

22 And I think that's ma -- some of the

1 major things that our committee talked about.

2 But, do you have other things?

3 So, it sounds like there's some  
4 concerns about the reliability from Sherrie. And  
5 Sherrie, is your card up new? Or is that a left  
6 over?

7 MEMBER KAPLAN: It's a left over.

8 MS. JOHNSON: Okay.

9 MEMBER KAPLAN: I am trying to keep my  
10 mouth shut on this. But, it -- see when a  
11 measure is reliable but not valid, it's  
12 consistently wrong.

13 So, just as my bathroom scale I always  
14 say is consistently wrong. I love my bathroom  
15 scale, it's consistently wrong.

16 But, in a way that's -- in some ways  
17 it's good news because you can recala -- if the  
18 thermometer is three degrees off, you know it's  
19 three degrees off.

20 But, you can't have a measure that's  
21 inconsistently right. So, when we say  
22 something's not reliable, but it is valid, that's

1 weird from a psychometric standpoint. That's  
2 really odd.

3 MS. JOHNSON: Um-hum.

4 MEMBER KAPLAN: Because -- so, in a  
5 way, if you fail the reliability criterion, the  
6 validity criterion gets almost uninterpretable.

7 And so, you know, this is making me  
8 get the briggies. Because I'm not sure what to  
9 do.

10 And we did it a couple of times today,  
11 where we said something was not reliable, but  
12 then it's valid. And I went, how do you do that?

13 MS. JOHNSON: Right.

14 MEMBER KAPLAN: So, you know, figuring  
15 out how to help advise committees on how to --  
16 when it doesn't pass the reliability issue, what  
17 are you going to do then with validity?

18 And if some of these things have  
19 trouble at the facility level, and it's being  
20 used at the facility level, -- and then they're  
21 not giving it, they're giving us data within the  
22 survey, which is still patient level.

1                   And they're not giving us any evidence  
2                   that -- except for maybe the shared decision  
3                   making one, where they looked at how mutable it  
4                   was, responsive it was, efforts to change the  
5                   scores.

6                   MS. JOHNSON:   Um-hum.

7                   MEMBER KAPLAN:   You know, that is  
8                   something that I'm struggling with.

9                   MS. JOHNSON:   That's a good point.  
10                  And you know, I'd be interested maybe offline.  
11                  Part of me wants to flip our criteria and do  
12                  validity first.   And then talk about reliability.

13                  MEMBER KAPLAN:   It won't help any.

14                  MS. JOHNSON:   It won't help any?  
15                  Okay.   I thought it might help though.

16                  MEMBER KAPLAN:   No, because the issue  
17                  is still the same.   You know, if it's  
18                  consistently wrong, okay.

19                  MS. JOHNSON:   Right.

20                  MEMBER KAPLAN:   But it can't be  
21                  inconsistently right.

22                  MS. JOHNSON:   Right.   Katherine, did

1       you have a question?

2                   MEMBER BEVANS:   This is actually a  
3       question for you.   Do you feel like people are  
4       getting -- really for the full committee, do you  
5       feel like people are getting tripped up in  
6       demonstrating that the measure is reliable at the  
7       individual level, and therefore moving forward  
8       with validity testing kind of at the individual  
9       level.

10                   But, really the issue is, they're not  
11       demonstrating validity at the aggregate level.  
12       And then in the case of like the shared decision  
13       making measure, they move forward at the  
14       aggregate level with demonstration of validity.

15                   So, is this confusion that people are  
16       having, confounded by the need to emphasize  
17       reliability testing at the aggregated, meaning at  
18       the clinic or provider, or whoever, level?

19                   Because somehow I just don't think  
20       that message is still getting to folks.   What are  
21       -- I mean, do you feel like these two issues are  
22       related?



1           MEMBER KAPLAN: I mean, the issue in  
2 reliability terms is, if you're trying to test a  
3 measure for use, you know, at the student or the  
4 patient level, or whatever, you stay at that  
5 level.

6           If now you're comparing schools or  
7 hospitals or whatever, you want evidence that  
8 it's -- that you can -- that it's reliable at  
9 that level. So, now you've taken it from the  
10 patient level, which everybody, you know, knows  
11 how to do, to a different level.

12           And by the way, in the Physician  
13 Compare, I just got a note from Physician  
14 Compare, they're struggling with the same thing.  
15 Because, you know, if you're trying to compare  
16 groups of physicians, one to another, then you  
17 have to have some confidence that the measure is  
18 reliable at the level you're comparing.

19           So, it changes the -- first of all, it  
20 changes the standard. And it changes how you  
21 evaluate it.

22           So, then to go on to say it's valid,

1       so it may be consistent, but it has trouble with  
2       validity, okay we get that. But, it can't be --  
3       you can't have an inconsistently valid item.

4               MS. JOHNSON: I guess final word. Any  
5       other feedback that you would like us to give to  
6       our palliative care committee?

7               MEMBER KAPLAN: Just one?

8               MS. JOHNSON: Yes.

9               MEMBER KAPLAN: Can I -- Karen, can I  
10      ask that there is a way to do generalized  
11      estimation equations that I've you the individual  
12      facility score with the standard error.

13              MS. JOHNSON: Um-hum.

14              MEMBER KAPLAN: And you plot those.  
15      And you see usually what looks like a snake. It  
16      will look like a spline.

17              Can they at least help us? Because  
18      what you'll see if it's not reliable, you'll see  
19      a big standard error bar. And you'll see you  
20      can't tell the difference between any facility in  
21      the distribution at all.

22              MS. JOHNSON: Huh. Okay.

1                   MEMBER KAPLAN: So, if they gave us  
2                   that, I think, Sarah I gave you one of the papers  
3                   that we had done with that spline, where it looks  
4                   like with enough items at the physician level,  
5                   you can actually distinguish the bottom cortile  
6                   from the top cortile.

7                   You couldn't distinguish one facility  
8                   from another. But, you could do that kind of  
9                   comparison.

10                  MS. JOHNSON: Right.

11                  MEMBER KAPLAN: So, maybe asking them  
12                  for some generalized estimation equation results,  
13                  or generate that kind of spline for us. Just to  
14                  show us the facility and the standard error bars.

15                  MS. JOHNSON: Okay. One of the things  
16                  that they did give in the time under validity on  
17                  meaningful difference, and I actually, honestly  
18                  kind of wondered about this.

19                  But, they did a -- they looked at the  
20                  hospice national average. And concluded that for  
21                  all eight of the measures, somewhere in the high  
22                  40 percent, there are different from the hospice

1 national average.

2 So, it's kind of smoke and mirrors a  
3 little bit. But, I think that's probably what  
4 they're trying to get too at least.

5 MEMBER KAPLAN: The problem is that  
6 again, if you sample a new bunch of patients from  
7 that facility, you could get a completely  
8 different answer.

9 So, if there's a lot of within  
10 facility variance, then the next time you go back  
11 to that facility, you could get a real goof ball  
12 answer. And it may not be what they're doing to  
13 them, but who they're attracting.

14 MS. JOHNSON: Um-hum.

15 MEMBER KAPLAN: That's why this  
16 components of variation thing that we've been  
17 talking about with Helen is so important.

18 MS. JOHNSON: Right.

19 MEMBER KAPLAN: Because if they can  
20 give us some sense that the facility level  
21 variance is this. Eight percent of the variance  
22 is attributable to the facility.

1           At least you'd have some confidence  
2           that, you know, you're not measuring something  
3           about the patients. You're measuring something  
4           about the facility.

5           MS. JOHNSON: Right. All right, I  
6           will see. Because they have a team. I mean, you  
7           know, the CAHPS machine is quite. Yes. Thank  
8           you guys.

9           MS. SAMPSEL: Well, thanks. And I  
10          think Kirsten, do you have a couple of next steps  
11          slides?

12          And then what we'll just do is kind of  
13          -- what we wanted to do is have a little bit of  
14          discussion about any gaps in the measure  
15          portfolio.

16          And you have a list of the full  
17          measure portfolio broken down into measures that  
18          are currently endorsed, measures that still need  
19          to be scheduled for maintenance review, those  
20          that lost endorsement.

21          Just get some general ideas if you  
22          think what's still missing in this portfolio.

1 And that's just -- goes into the measure report.

2 And is an indication to developers and  
3 others that there's still, you know, there's an  
4 interest in these measures. And just kind of for  
5 future reference for us as well.

6 And then, you know, as Peter  
7 suggested, and I think as we've talked about, you  
8 know, work -- I don't want to say we're  
9 struggling with, but this committee has a lot of  
10 difficult measures all the time.

11 And so, there are times when some of  
12 these measures coming in are getting ahead of,  
13 you know, really the ability to translate them  
14 into these forms. Translate how we would  
15 interpret the criteria, et cetera.

16 So, I do think some reflections over  
17 the past couple of days, and what we can continue  
18 to learn and grow, and improve our processes  
19 would help as well.

20 CO-CHAIR PARTRIDGE: And I would like  
21 to add on that last point. We specifically,  
22 Chris and Sarah and Karen and I, had both email

1 and over the phone, and Sherrie's been part of  
2 some of this, a feeling that maybe some of the  
3 algorithms we use for the PRO-PMs need to be  
4 looked at again.

5 There -- I forget when that committee  
6 report was probably at least -- I should say at  
7 least almost three years back.

8 And we've been struggling with some of  
9 these PRO-PMs. And maybe they're still fine.

10 But, I think there was some sense that  
11 maybe -- maybe either we needed to rephrase them  
12 so that they were easier for the standing  
13 committee members to use. We weren't quite sure.

14 MS. SAMPSEL: But I think it's broader  
15 then that. And I just want to make sure that's  
16 out on the table.

17 It's not just the PRO-PMs. It's any  
18 of the tool-based measures. And that's what  
19 we're trying to do internally, is make that  
20 distinction.

21 That certainly it happens with the  
22 PRO-PMs. That's where, I think, we first

1 encountered our greatest difficulties.

2 But now that we have the FIM, the  
3 CARE, the CoreQ, you know, all of those things.  
4 That we really need to make it broader. And so,  
5 if some of that feedback is on the table too.

6 So, just really kind of bring up real  
7 quick, next steps. Right now we don't have to  
8 have the post-meeting conference call next week.

9 So, let us internally have our staff  
10 meeting tomorrow. Make sure that all business  
11 has been covered. But, I think for the most part  
12 it is. It has been.

13 And then, in the meantime, over the  
14 next five weeks, staff are writing our draft  
15 report. You guys typically get a heads up before  
16 it goes out for public comment.

17 But, then it's out for public comment  
18 for four weeks. That's the period that any of  
19 those consensus not reached measures that we're  
20 working with the developers for those to get  
21 additional data back to see if we can bump up  
22 those scores at all, because you'll revote on



1 consensus not reached.

2 The post-draft report comment call, I  
3 believe there's a Doodle poll or something out  
4 trying to find out when we're going to have that.  
5 Because we had some scheduling difficulties.

6 And then we still have member votes,  
7 CSAC review, Board review, and appeals to  
8 hopefully finish this all up by the end of the  
9 year. That looks like a good Thanksgiving gift.

10 CO-CHAIR PARTRIDGE: Becky?

11 MEMBER BRADLEY: Could you explain the  
12 endorsement removed? What does that mean when an  
13 endorsement is removed?

14 And is it NQF removes it or the  
15 developer removes it? I've just noticed several  
16 on this list we're voting on.

17 MS. SAMPSEL: Yes, I would say that  
18 list specifically, a good portion of those  
19 measures are AHRQ, they're CAHPS measures. The  
20 skill -- both cultural literacy measures out of  
21 the CG CAHPS, and then the SNF Chaps.

22 And so those AHRQ indicated they were

1 not going to maintain the measures. They're  
2 maintaining the tools and the instruments, but no  
3 longer the performance measures that go with  
4 those.

5 So basically, in a conversation with  
6 them, they indicated they would not maintain the  
7 measures. And therefore endorsement was removed.

8 I think there are two NCQA measures on  
9 that list as well. And both of those, I think  
10 one they decided just wasn't applicable for  
11 measures.

12 They felt they were more applicable  
13 for standards. So, they weren't going to  
14 maintain those. And then the other was a health  
15 outcome survey measure, the urinary incontinence  
16 measures.

17 NCQA's doing some considerable work on  
18 the measure. They've been doing it for a long  
19 time. So, it's well past it's maintenance. And  
20 they asked for endorsement to be removed while  
21 they reconfigure the measure.

22 CO-CHAIR STILLE: Just a quick

1 housekeeping thing. When are we going to talk  
2 about the related and competing measures?

3 You're not working, okay. Sounds  
4 good.

5 MS. SAMPSEL: That was a --

6 CO-CHAIR STILLE: Some other day.

7 MS. SAMPSEL: Yes. No, that was the  
8 thing, you know, we need a little time on that.  
9 Because those are the functional status measures.

10 And I think there are some really big  
11 implications that we don't want to hurry the  
12 discussions. And especially since with the long  
13 term care measures didn't have the same  
14 disposition as the SNF measures, which didn't  
15 have the same disposition as the IRF measures.

16 I think we really need to look at  
17 that. So, I'm thinking it's going to be post-  
18 public comment.

19 CO-CHAIR STILLE: Okay.

20 MEMBER HOY: Yes, didn't -- and this  
21 may be addressed later then, the UDSMR measures.  
22 Some of them were almost related or competing

1 with themselves, right?

2 In the fact that they were  
3 encompassing one another almost. So they were  
4 submitting it twice.

5 So, I guess is that for that  
6 conversation then?

7 MS. SAMPSEL: Yes. So, that's one of  
8 my areas of great difficulty. In looking at  
9 these, and you know, just in this review for the  
10 past two days, the UDSMR measures are related to  
11 each other. Same focus area, different  
12 population.

13 However, the SNF group of those  
14 measures, at least the self-care and mobility,  
15 are competing with some measures that came  
16 through last cycle. And then the long term care  
17 ones are probably related to some that came  
18 through the last cycle.

19 So, I really just want to take some  
20 time to be able to spell that all out and give  
21 folks the points of comparison. So that we can  
22 really walk through.

1           The other background for those of you  
2 new to the committee is, we had a similar  
3 discussion in phase two, and we did not come to  
4 consensus on some competing measures. And if  
5 there was a best in class.

6           And so, we really want to think  
7 through that. And you know, kind of figure out  
8 not only implications, but how that would move  
9 forward.

10           And so, I want to make sure you all  
11 have the best information to do that.

12           MEMBER BEVANS: That's okay, it  
13 happens all the time for some reason. I don't  
14 know if this is the right time, so just tell me  
15 if it isn't.

16           But, for comments that we may have  
17 about the criteria themselves, should we just  
18 offer those now?

19           Something that I noticed in our last  
20 review, and especially even more so in this  
21 round, is that the criteria somehow don't seem to  
22 be encouraging, or the forms or something, don't

1        seem to be encouraging developers to provide a  
2        lot of information about the content validity of  
3        the measures.

4                In particular, cognitive testing,  
5        qualitative methods that people are using to  
6        verify that the measures that are being proposed  
7        are understood, meaningful, and I mean the actual  
8        items. Meaningful, important and so onto the  
9        population in which they're proposing their  
10       application.

11               People seem to talk about that, but  
12       sometimes as an afterthought. And I think it's  
13       such a critically important component of the  
14       overall quality of a measure.

15               That it's understood. You know that  
16       it is meaningful and important to the population  
17       of interest.

18               And so, I guess I'm just wondering, is  
19       there a possible -- is there a way to kind of  
20       reconsider that validity criteria to call out  
21       specifically content validity?

22               Because, you know, in many cases

1 actually we saw evidence of people having done  
2 some of those procedures. This is a lot of work.  
3 It takes -- it's a lot of effort. And if it's  
4 missing, it really calls into question the  
5 overall validity of the measures.

6 So, just a thought about that.

7 MEMBER KAPLAN: In some of these, some  
8 of the measures we saw are old in the sense that  
9 they've been around a long time. So, patient  
10 engagement is a very new construct, concept.

11 But, it's like -- it's -- some of  
12 these measures, not to defend these one way or  
13 another, but some of them have been around for --  
14 they were developed a fair amount of time ago.

15 And then the question is, well then  
16 should you not, you know, resurface these  
17 measures with a group of folks? You wouldn't  
18 expect them to do a whole new content validity  
19 with focus groups and reinvent these things.

20 But, maybe what you're saying is you  
21 should check base with some subgroup of folks and  
22 make sure they're still relevant to these?

1                   MEMBER BEVANS: I think it depends on  
2 who asks with respect to the content validity  
3 question. Because there's two thoughts about  
4 this one.

5                   Is that the measures are developed and  
6 the content validation work is done with one  
7 population. And therefore, it's applicable over  
8 time and with other populations.

9                   But what we're seeing are measures  
10 that are being proposed for use in very specific  
11 population. For example, today our chair  
12 decision making for seven surgical conditions.  
13 And you know, if you asked the FDA, they would  
14 say content validation needs to be done at the --  
15 within the specific population that we're  
16 recommending a measure to be used.

17                  MEMBER KAPLAN: Where it's more  
18 meaning, things like frailty and functional  
19 status and those kinds of things that have been  
20 around a fair amount of time. Not the newly  
21 developed ones at all.

22                  MEMBER BEVANS: No.



1 CO-CHAIR PARTRIDGE: I'm going to make  
2 a pitch for pediatric. Chris and I do it all the  
3 time.

4 CO-CHAIR STILLE: Yes, well me too.  
5 Right.

6 CO-CHAIR PARTRIDGE: But, again at  
7 this time --

8 CO-CHAIR STILLE: As always.

9 CO-CHAIR PARTRIDGE: We with the 18  
10 and above, and yet we keep thinking that some of  
11 them anyway, I guess your comment on the hospice  
12 probably would work perfectly well.

13 CO-CHAIR STILLE: Sure. You know, one  
14 of the things that they do I think in like NIH  
15 and AHRQ grants and stuff, is you have to provide  
16 a rationale if people under 18 are not included.

17 And I think that would be really  
18 helpful. And sometimes the rationale is easy.  
19 But other times it's sort of like, yes, well we  
20 didn't really want to be bothered or we don't  
21 have enough data or something like that.

22 And that's not necessarily a good

1       excuse. So, I think even a simple rationale for  
2       not including people under 18 would be super  
3       helpful.

4               The other thing is, I was so happy to  
5       see the shared decision making measure come up.  
6       And there's lots and lots of room for that, for  
7       kids as well as adults.

8               CO-CHAIR PARTRIDGE: I guess I would  
9       also, to the extent we can, go back in some of  
10      the measures we've endorse. For example, I  
11      remember Eric Coleman saying that he was working  
12      on a pediatric version of the CTM.

13              If that's so, we'd love to see it.  
14      And we don't know what it would have. Well,  
15      okay. But, yes you're right. It has been  
16      floated into CAHPS.

17              There's also a new -- a shorter  
18      version of CAHPS floating around, but we've not  
19      seen. Do they have to come through with that?

20              DR. BURSTIN: It's still -- my  
21      understanding is, it's still being tested in  
22      California. So, again the length of some of

1       these surveys always comes up.

2               So, there's been a fair amount of  
3       testing on a shorter version. We will encourage  
4       them to bring it forward.

5               And to Chris' point about pediatrics,  
6       some of our clinical committees, for example, our  
7       surgery committee, we always have two -- we've  
8       had two pediatric surgeons on there for years.

9               And they're always the ones who say,  
10      so is there any reason for the 18 cut off? And  
11      you know, it's interesting because we now have a  
12      space on the form where we specifically ask about  
13      whether there's any evidence of disparities.

14              This is an interesting idea to  
15      actually ask for justification of the ages at  
16      either end. Actually this issue is equally  
17      applicable in terms of why is the cutoff at 70 or  
18      80, or you know, maybe just something specific to  
19      age and its rationale is something for Karen to  
20      kind of build in going forward.

21              CO-CHAIR STILLE: I think there was  
22      one maybe in phase one that we talked about, you

1 know, do you have data for people under 18? And  
2 they actually had data for people 14 and up.

3 Which, you know, was at least a step  
4 in the right direction.

5 CO-CHAIR PARTRIDGE: That was Judy  
6 Hibbard.

7 CO-CHAIR STILLE: Okay.

8 CO-CHAIR PARTRIDGE: And they didn't  
9 have that many people that maybe modified.

10 CO-CHAIR STILLE: They thought they  
11 did. Okay.

12 CO-CHAIR PARTRIDGE: They were not  
13 contributable.

14 CO-CHAIR STILLE: Okay. All right.

15 MEMBER THOMAS: Discussion about gaps  
16 prompts a question. And this strikes me that  
17 this is kind of an investigate or initiated  
18 process.

19 People come to the NQF to get their  
20 measures validated. But, does the NQF ever put  
21 out what amounts in this research circles to an  
22 RFP or an RFA? And request measure sets in

1 certain areas to fill gaps?

2 DR. BURSTIN: So, it's an interesting  
3 question, Peter. There's a couple of different  
4 ways we do that.

5 Certainly at the start of projects, we  
6 try to take the gaps you've already identified  
7 and put that out there as part of the call for  
8 measures. It's often a little bit too late.  
9 People are already kind of bring forward things  
10 they've worked on for the year.

11 So, we need to do a better job of  
12 that. I don't know if we've shared the document  
13 with this group, but we should. We have just a  
14 one page around our new strategic plan.

15 And one of the things that we've  
16 identified clearly in there is that NQF will take  
17 a very clear role in identifying the highest  
18 prioritized measures and the highest prioritized  
19 gaps. And we'll develop a set of criteria to use  
20 that.

21 So, we're hoping that will, you know,  
22 push people in the directions of filling what we

1 know are national gaps.

2 And then also again, I don't know if  
3 you've talked about it, but we've also formed the  
4 measure incubator. Where we have the ability to  
5 have folks come forward with ideas for measures  
6 and try to hook them up with resources and  
7 others.

8 And interestingly, the measures we've  
9 seen most commonly come to the incubator are all  
10 PROs. So, we've got a couple of new measures.

11 We've got some new COPD PRO-based  
12 measures being incubated as well as some new work  
13 we're just going to launch on PROs for multiple  
14 sclerosis and everywhere that we have no quality  
15 measures of any kind. So, some real nice  
16 opportunities there.

17 And maybe in some future discussions  
18 we can share some of those materials with this  
19 group.

20 MEMBER THOMAS: Well, I just love to  
21 -- and on the issue of gaps, I'd love to just put  
22 in another plug. I've said this already about

1 the next level of functional measures.

2 So that they're not so tied to  
3 traditional inpatient settings. And that you  
4 really get to functional restoration and becoming  
5 independent and, you know, all the things that  
6 come with that.

7 And measuring those things are real  
8 true outcomes of what people are really looking  
9 for after an illness or an injury.

10 DR. BURSTIN: I should also mention we  
11 have a grant with PatientsLikeMe. Some of you  
12 may know this group in Cambridge.

13 So, we have a grant with them to look  
14 at what is the pathway towards developing these  
15 PRO-based performance measures. With a lot of  
16 the emphasis really talking to patients about  
17 what they care about and what they think  
18 clinicians should be held accountable for.

19 So, kind of taking it down to more of  
20 a really understanding of patients' viewpoints of  
21 what's most important here. But also, we'll work  
22 with them about thinking about developing.

1           And one of the ideas is actually just  
2   to focus on a set of symptoms for example,  
3   instead of functions. Rather then tying it to a  
4   clinical area even or a clinical setting at all.

5           But, great suggestions.

6           MEMBER MELILLO: So, I'd like to ask  
7   the group if -- well, let me back up a step. For  
8   the post-acute setting, quality measures and  
9   metrics are really exploding at the moment.

10          And what I saw a little bit of with  
11   the EDSMR measures is a tendency to think that  
12   you can take it from one setting and apply it to  
13   another. And I'm wondering if there's -- if that  
14   would be considered a gap?

15          That we need more measures that are  
16   setting specific.

17          MEMBER BRADLEY: I think part of what  
18   we're seeing is that CMS has mandated through the  
19   IMPACT Act that we have measures that cut across  
20   all the post-acute. And I think that's why we're  
21   seeing vendors or developers like UDS come in and  
22   -- because that is the directive for post-acute.



1                   So, it would be inconsistent I think  
2                   to encourage measurement development that's site  
3                   specific given our mandate. And we know that  
4                   that's where our funding is going to be in the  
5                   next few years.

6                   So, it is a dilemma.

7                   MEMBER MELILLO: It is. But just for  
8                   example, in LTAC environment, we'll have  
9                   ventilators and measures of that sort. Whereas  
10                  an IRF will not.

11                  So, I mean, there are definitely major  
12                  differences in the levels of care. And I  
13                  understand that the directive for IMPACT is to  
14                  kind of standardize these cross setting measures.

15                  But, I think that there maybe should  
16                  be some measures, maybe in addition, that are  
17                  site specific. So that we can get to really what  
18                  is the nature of each of those settings. Because  
19                  they are different.

20                  DR. BURSTIN: I don't think there's  
21                  anything that precludes that from happening as part  
22                  of IMPACT. I think there was a desire to have

1 some of that kind of across the settings.

2 But, there are going to be unique  
3 features of an LTAC that are just simply not  
4 applicable to a SNF or an IRF. That we want to  
5 make sure that patients and others have  
6 information that's really relevant to being on an  
7 ventilator at a long term acute care hospital.

8 So, I don't think it's either or. I  
9 think it's a good gap. Measures that are really,  
10 truly specific to a given setting.

11 It's sort of different I think then  
12 what Peter's saying is, in some ways there is  
13 going to be some measures unique to that setting.  
14 That we don't want to lose what's special and  
15 unique about that setting and capture that as  
16 well.

17 MEMBER FRIEDMAN: I'm really  
18 interested in measures around quality for  
19 unprecedented partnership between large health  
20 systems and community-based agencies.

21 You know, we're entering a time, I'm  
22 speaking for Kaiser, but for large systems where

1 we're seeing a large need to -- for social  
2 determinants of health.

3 And that there's a fear that, you  
4 know, we don't want to become a social service  
5 agency. But how do we partner with high quality  
6 vetted community agencies.

7 And it's a challenge to know A, what  
8 are those quality agencies? And what does good  
9 partnership look like?

10 So, I'd like to see those.

11 MEMBER KAPLAN: I would make a pitch  
12 for expanding the informed and shared decision  
13 making group, Helen. To include more broad  
14 teaching of how to be an effective consumer of  
15 health care.

16 You know, not just shared decision  
17 making which is a fairly narrow thing. But, how  
18 to choose and change a provider. How to use the  
19 healthcare system to your best advantage. How to  
20 be media savvy. How to interpret quality data.

21 You know, the idea that shared  
22 decision making is one area, but it's, you know,

1       there's a lot more to it than that.

2                   MEMBER MELILLO:   So, I'd also like to  
3       make a pitch for measures that would be across  
4       the continuum of care.   So, starting in either a  
5       physicians's office, primary care, or ER, all the  
6       way through to when they finish with services or  
7       they're as healed as they can be.

8                   I just think that's something that I  
9       haven't seen captured in any particular  
10      instruments that are out there.

11                  CO-CHAIR STILLE:   And actually Nicole,  
12      thanks for bring that up.   It sort of rang a bell  
13      that we're very good -- well, we're getting good  
14      at measuring the medical home.

15                  But really the medical neighborhood  
16      which extends beyond the medical home, and even  
17      beyond the, you know, medical environment into  
18      the community is huge.

19                  And, you know, as we work with  
20      patients and families, their care map has, you  
21      know, one quarter which is their medical stuff.  
22      And then three quarters, which is community, the

1 educational system if you're a kid, you know,  
2 family and that kind of thing.

3 And to the extent, you know, it's  
4 going to be baby steps, but to the extent that we  
5 can measure connection with important, consistent  
6 outside entities that are involved in their care,  
7 I think we're going to do better. Maybe the  
8 incubator is a good place to start with that.

9 MEMBER THOMAS: I guess I got a  
10 potential gap in process. I'm hearing and  
11 getting a lot of chatter on the email about our  
12 consideration of the home and community based  
13 services measure yesterday.

14 And how there is an NQF quality  
15 committee on home and community-based services.  
16 And they're going to be releasing a report next  
17 week that provides a quality framework for HCBS  
18 quality and highlights the importance of certain  
19 domains, et cetera.

20 So, I guess my question is, to what  
21 extent do the committees communicate with each  
22 other and one kind of lays out? You know, it

1 just strikes me that maybe there is a little bit  
2 of a disconnect there.

3 Maybe not. I'm just asking the  
4 question.

5 MS. SAMPSEL: No. So, I'll start.  
6 So, Karen's one example of coming, for kind of  
7 having some of that committee overlap and  
8 ensuring that we're exchanging information.

9 And then HCBS is an example.  
10 Disparities is an example. The MAP work that we  
11 do is an example for in helping the rule making.

12 And that's where at the staff level  
13 we're ensuring that the other groups and  
14 committees, at least their staff, are aware of  
15 what we're working on.

16 And so in this case, with the HCBS  
17 measure specifically, that entire team knew about  
18 that. And then they were asked to inform their  
19 committee of the deliberations as well as the  
20 Duals Workgroup, of the deliberations of this  
21 committee.

22 So, it's happening. The one

1 difference with HCBS is that's not a consensus  
2 development project. So, they're not involved in  
3 kind of the recommendations of endorsement.

4 They were a framework project. Which  
5 of course, you know, we would eventually have fed  
6 into.

7 So, the communications are happening.  
8 We actually encourage them to comment in the pre-  
9 evaluation comment. And then they have another  
10 opportunity to comment during public comment.

11 And we'll reach out to the team again  
12 to remind them that they can comment to us. And  
13 so you don't have to get all of the emails.

14 Elisa, did you want to add to that?

15 MS. MUNTHALI: Only to add that the  
16 team, the HCBS team is listening in. Some of  
17 them were here in the last two days.

18 And they will be updating the report  
19 accordingly based on what happened here.

20 CO-CHAIR STILLE: Okay. Well, thanks,  
21 have a great trip back and thank you, Lee.

22 MS. SAMPSEL: Well, before you walk

1 off, thank you Lee. And thank you Chris for  
2 leading.

3 (Applause.)

4 CO-CHAIR STILLE: We have to open the  
5 phone lines for member and public comment. Okay.  
6 Let's do that.

7 MS. THEBERGE: Operator, can you open  
8 the line for comment?

9 OPERATOR: Yes, ma'am. At this time  
10 if you would like to make a comment, please press  
11 star then the number one.

12 There are no public comments at this  
13 time. I apologize, you do have a public comment  
14 from Paulette Niewczyk.

15 MS. THEBERGE: Okay.

16 DR. NIEWCZYK: Hello?

17 MS. THEBERGE: Hi, we can hear you.

18 DR. NIEWCZYK: Hi, thanks. I just  
19 want to remind the committee that the measures,  
20 the functional measures that we have put forth  
21 for consideration, it was with the intention that  
22 they could be used across post-acute care venues.



1           Since that was not only one of the  
2           requirements of the IMPACT Act, but really it was  
3           something that was put forth with the PAC-PRD as  
4           being, you know, really of major importance.

5           So, that's something that with that in  
6           mind. But also, these measures are just one  
7           portion. We certainly understand that there are  
8           other measures that would be appropriate for an  
9           LTAC, or for a SNF, or for an IRF.

10          So, this is something that would be  
11          just looking at certain functional domains.  
12          Whereby other measures could also be collected in  
13          those site specific venues.

14          So, I just want to add that  
15          clarification.

16          MS. THEBERGE: Thank you. Are there  
17          any other comments?

18          OPERATOR: Okay. At this time there  
19          are no comments.

20          MS. THEBERGE: Okay. I think that  
21          concludes this meeting.

22          MS. SAMPSEL: Well, I was just going

1 to -- Peter, did you have other comments about --

2 MS. THEBERGE: Thank you very much  
3 everyone.

4 MEMBER CELLA: Bye, bye.

5 MEMBER THOMAS: Just real quickly. I  
6 can't -- I guess I should put it on the table. I  
7 kind of feel maybe people in the room will  
8 strongly disagree with me. I don't know.

9 I kind of feel there was a little bit  
10 of, maybe we were low on blood sugar yesterday  
11 afternoon. But, we kind of treated the UDS  
12 measures on long term acute care hospitals pretty  
13 negatively.

14 When I heard some other things today,  
15 in particular with respect to the shared decision  
16 making data, that was pretty similar to what I  
17 heard yesterday afternoon. But, we gave them --  
18 that measure better grades on average.

19 Now, it's not apples to apples by any  
20 means. But, I'm just -- maybe it goes, Sherrie,  
21 to your comment about some of the inconsistency  
22 with some of what we're -- how we're judging some

1 of these things. So --

2 MEMBER KAPLAN: Well, I think when a  
3 measure is fairly mature, it's reasonable to  
4 expect a different level, a different standard  
5 from when it's very new. And again, NQF doesn't  
6 have yet a phased development kind of standard  
7 for us to kind of vary those psychometric, you  
8 know, standards to apply.

9 So, when you see a new measure that's  
10 got very limited data because it isn't using  
11 traditional data collection methods. It isn't  
12 out there.

13 The lac -- you know, being a little  
14 more lenient with the psychometric standards of  
15 it seems to me very reasonable when you're first  
16 starting off.

17 On the other hand, when you're using  
18 pretty well collected data, or when you're using  
19 a standard that -- of measures that have been out  
20 there for a fair amount of time and you've got a  
21 vast database to work with, then it is a -- in my  
22 view, it is reasonable to expect more from those

1 kinds of data.

2 Especially when there's millions of  
3 cases or thousands of cases. And there's, you  
4 know, hundreds of facilities and so on.

5 So, I don't feel badly about holding  
6 new -- relatively new measures to a different  
7 standard of -- different psychometric standard  
8 for myself then I do for measures that have been  
9 out there for a fair amount of time and are well  
10 used, and we know a lot about how they perform at  
11 certain levels.

12 So, I'm not -- if that was the issue  
13 and you know, you sensed something from me, I was  
14 reacting to how much we know about the  
15 performance of the measures yesterday versus the  
16 performance of the measures today, in their phase  
17 of development.

18 MEMBER THOMAS: No, I asked you  
19 because I thought that you had picked up some of  
20 the same thing with respect to what you had seen  
21 -- the issue between reliability and validity.

22 And what you had -- the point you had

1 made about how you can't really vote in favor of  
2 one, and yet we were. That kind of point.

3 That's why I --

4 MEMBER KAPLAN: I didn't, you know, I  
5 kind of didn't say that yesterday. I probably  
6 should have gone over that.

7 It is, you know, it is an issue for  
8 when you're talking about reliability and  
9 validity. It is an important issue to kind of  
10 keep in mind.

11 But again, you know, when you've got  
12 limited data to address the reliability issue,  
13 you can't really do, you know, what we did  
14 either. You know, it doesn't make it any better.

15 It's just that when the measure isn't  
16 -- we don't have much information about how it's  
17 performing, it's much harder to make the case  
18 that well, here's what we should have seen, and  
19 here's what we did see.

20 And so, and then when we ask the  
21 questions, we didn't get the kinds of responses  
22 you would have expected for a group that

1 understands what the need is. And then how to  
2 respond to it.

3 Oh, yes, we can do that. We can get  
4 those data back to you, no problem. And in fact,  
5 in other committees that I've been involved in,  
6 when you give that kind of request to the measure  
7 developer, some of them just go right back and  
8 they'll give you what you want.

9 MS. SAMPSEL: All right. Any last  
10 thoughts? If not, we're really done this time.

11 I really want to thank everybody. And  
12 you know, certainly to the folks who left as  
13 well. We appreciate you committing to this. And  
14 we know it's a lot of work and a lot of brain  
15 function. So, thank you. And I hope everybody  
16 has safe travels.

17 (Whereupon, the above-entitled matter  
18 went off the record at 1:36 p.m.)  
19  
20  
21  
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Before: NQF

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