

NATIONAL QUALITY FORUM

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PERSON- AND FAMILY-CENTERED CARE
STANDING COMMITTEE

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MONDAY
JULY 28, 2014

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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 9:00 a.m., James Merlino and Lee Partridge, Co-Chairs, presiding.

PRESENT:

JAMES MERLINO, MD, Co-Chair

LEE PARTRIDGE, Co-Chair

KATHERINE BEVANS, PhD, University of
Pennsylvania School of Medicine,
Children's Hospital of Philadelphia
SAMUEL BIERNER, MD, UT Southwestern Medical
Center

REBECCA BRADLEY, LCSW, HealthSouth
Corporation

SHARON CROSS, LISW, The Ohio State
University, Wexner Medical Center

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

CAROL LEVINE, MA, United Hospital Fund

BRIAN LINDBERG, BSW, MMHS, Consumer
Coalition for Quality Health Care

SHERRI LOEB, RN, BSN, EMMI Solutions

LISA MORRISE, MA, National Partnership for
Patients

ELIZABETH MORT, MD, MPH, Massachusetts
General Hospital, Massachusetts
General Physicians Organization*

ESTEE NEUWIRTH, PhD, Kaiser Permanente Care
Management Institute
LENARD PARISI, RN, MA, CPHQ, FNAHQ,
Metropolitan Jewish Health System
DEBRA SALIBA, MD, MPH, UCLA/JH Borun Center
for Gerontological Research, VA,
Greater Los Angeles GRECC, RAND Health
CHRISTOPHER STILLE, MD, MPH, FAAP,
University of Colorado School of
Medicine, Children's Hospital Colorado
PETER THOMAS, JD, Powers Pyles Sutter &
Verville P.C.
CARIN VAN ZYL, MD, FACEP, City of Hope
National Medical Center

NQF STAFF:

NADINE ALLEN, Project Analyst, Strategic
Partnerships
HELEN BURSTIN, MD, MPH, Chief Scientific
Officer
LAURALEI DORIAN, MPH, Project Manager,
Performance Measurement
KAREN JOHNSON, Senior Director, Performance
Measurement
KAREN BECKMAN PACE, PhD, RN, Senior
Director, Performance Measurement

ALSO PRESENT:

ERIC COLEMAN, MD, MPH, University of
Colorado School of Medicine*

BARBARA CRAWLEY, Centers for Medicare &
Medicaid Services (CMS)

MARY ERSEK, PhD, RN, FAAN, University of
Pennsylvania School of Nursing,
Veterans Health Administration PROMISE
Center*

LIZ GOLDSTEIN, Centers for Medicare &
Medicaid Services (CMS)

MATTHEW HASKINS, MPH, CPH, National Hospice
and Palliative Care Organization*

THOMAS JAMES III, MD, AmeriHealth Mercy
Family of Companies (AMFC), NQF Health
Plan Council*

WILLIAM LEHRMAN, Centers for Medicare &
Medicaid Services (CMS)

CAROL SPENCE, PhD, RN, National Hospice and
Palliative Care Organization*

LORI TEICHMAN, Centers for Medicare &
Medicaid Services (CMS)*

JOAN TENO, MD, MS, Brown University*

* present by teleconference

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Adjourn

1 We have three dedicated breaks
2 today, one at 10:45, lunch will be served
3 provided by NQF at 12:15, and another break at
4 3:15.

5 We do have WiFi here. The
6 username is guest and the password is
7 NQFguest.

8 This call is, as all of our calls,
9 open to the public, so please remember to mute
10 your lines if you're on the phone. It just
11 helps with the noise.

12 All of the materials are available
13 via SharePoint. We will be screen sharing
14 today and we have a Webinar, so please email
15 me, Lauralei, if anybody on the call has any
16 questions or is having any difficulty
17 accessing the materials.

18 We have made reservations tonight
19 at 6:00 p.m. at a place called Mio for dinner,
20 which is a really good contemporary Latin
21 American place just around the corner from
22 here. So at lunch I'll ask if anybody's

1 interested and I can let them know of the
2 specific numbers.

3 So with that, I will have the rest
4 of our NQF staff introduce themselves. I'll
5 begin with Helen Burstin, who is our chief
6 scientific officer.

7 DR. BURSTIN: Good morning,
8 everybody. Pleasure to be here with you
9 today. We're looking forward to these
10 meetings. These are among the most important
11 measures in our portfolio, so really thrilled
12 in particular to have so many consumers and
13 patients at the table with us. So I'll have
14 a chance to re-engage with you in a few
15 moments as we do introductions and
16 disclosures.

17 DR. PACE: I'm Karen Pace and I'm
18 senior director on the project and will just
19 notify you now that I'll be departing from NQF
20 in a few weeks and Sarah Sampsel, who is here
21 and will introduce herself in a moment, will
22 take over for me. So should have a smooth

1 transition.

2 MS. ALLEN: Hi, I'm Nadine Allen.
3 I'm project analyst on this project.

4 MS. JOHNSON: Good morning. My
5 name is Karen Johnson. I am a senior director
6 here at NQF.

7 MS. SAMPSEL: Good morning. I'm
8 Sarah Sampsel and as Karen kindly just
9 introduced me, I will be taking over as senior
10 director on the project and I'm a consultant
11 to NQF.

12 DR. PACE: And, everyone, these
13 microphones, you will have to get them close.
14 We do have people on the Webinar and also a
15 transcriptionist, so it's important that we
16 speak into the microphones. Thanks.

17 MEMBER THOMAS: My name is Peter
18 Thomas.

19 MS. DORIAN: So --

20 MEMBER THOMAS: Oh, forgive me. I
21 thought we were going around.

22 MS. DORIAN: We'll do the internal

1 NQF staff first. But now actually that's a
2 perfect segue.

3 (Laughter)

4 MS. DORIAN: We're going to have
5 -- so thank you.

6 MEMBER THOMAS: Didn't mean to
7 force the issue.

8 MS. DORIAN: No, no, no. Helen
9 Burstin is going to lead our disclosure of
10 interest process. We'll do introductions with
11 that.

12 DR. BURSTIN: Right, so we'll do
13 introductions as part of this process. So
14 part of what we try to do is try to be as open
15 as we can about anybody's potential biases or
16 conflicts. We recognize we can't exclude
17 every single one of them, or we wouldn't have
18 anybody at the table. So we are fully
19 cognizant of that, but want to have the
20 opportunity for all of you in particular to
21 understand where each of you is coming from
22 and see if you have any potential biases or

1 disclosures that you think would be of
2 importance to share.

3 We don't need you to recite your
4 CV; we'd be here for days, or your résumé or
5 anything along those lines. So what we really
6 want you to do is introduce yourself, tell us
7 your position, where you are. And if there's
8 anything that you think is particularly
9 relevant to the measures before the Committee
10 over the next two days, please, please share
11 those.

12 And we'll begin with the Chairs.

13 Jim?

14 CO-CHAIR PARTRIDGE: Good morning,
15 everyone, and welcome to this Committee and to
16 the NQF process, if you are new to it. I'm
17 Lee Partridge and I'm going to co-chair this
18 group over the next couple of years, which is
19 a delight for me both because I love NQF and
20 the work we do here, but I'm really pleased
21 that we are starting a standing committee
22 process in which we get to work together for

1 a serious length of time as opposed to being
2 pulled together on an ad hoc basis.

3 I am the senior health policy
4 advisor at the National Partnership for Women
5 and Families, which is a 45-year-old advocacy
6 organization here in Washington, although I am
7 now no longer living in Washington. I'm
8 located in Midtown, New York.

9 CO-CHAIR MERLINO: Thanks, Lee.
10 I'm Jim Merlino. I'm a colorectal surgeon at
11 the Cleveland Clinic. I'm also the chief
12 experience officer and the associate chief of
13 staff. And it's my first time a part of this
14 Committee and I'm very excited because I think
15 the work that the NQF does and the measures
16 that it reviews and ultimately approves is
17 really critical for improving how we deliver
18 health care. And I think that how we take
19 measurement to the patient and allow them to
20 provide feedback to both drive policy,
21 regulatory environment and also hospital
22 operations is really critical.

1 And it's interesting: I was flying
2 out here this morning thinking about what an
3 awesome responsibility this really is. When
4 you think about it, it is a triangle. At the
5 top of that triangle are what we do for
6 patients, because this really -- these
7 measures have the potential, just as all the
8 measures that are currently active, to really
9 bring the voice of the patient and the voice
10 of the family into hospital operations.

11 But I think we also have an
12 ultimate responsibility that we have to ground
13 that triangle on the other two tips, which is
14 to look at the process in a very open
15 objective light, make sure that we are
16 approving things that are going to be able to
17 be successfully operationalized across
18 hospitals in the United States, and also
19 approve measures that the Government on the
20 other tip of the triangle is able to really
21 use effectively to drive reimbursement and
22 also improvement in health care.

1 So it is an awesome responsibility
2 and I'm happy to be a part of it. And thank
3 you for all of you, your willingness to put
4 time in this as well.

5 MEMBER BIERNER: I'm Sam Bierner
6 from the University of Texas, Southwestern
7 Medical Center, a professor of physical
8 medicine and rehabilitation and I don't have
9 any conflicts of interest that I know of or
10 financial interests that would involve here.

11 MEMBER CROSS: Hi, my name is
12 Sharon Cross. I'm from Ohio State University
13 Medical Center and I work in our Patient
14 Experience Department overseeing our Patient
15 and Family Advisory Council. I don't believe
16 I have any conflict of interest.

17 MEMBER BRADLEY: I'm Becky
18 Bradley. I work for HealthSouth Corporation
19 in Birmingham, Alabama. We have 104 inpatient
20 rehabilitation hospitals, post-acute, in 27
21 states, so we have multi-cultural patients and
22 families. And they're small hospitals, but --

1 it's a big company with small hospitals across
2 the nation. And I have no conflict of
3 interest to disclose.

4 MEMBER SALIBA: I'm Debra Saliba.
5 I'm an internal medicine physician who
6 specializes in geriatrics. I work at UCLA
7 where I'm a professor of medicine and direct
8 the Borun Center for Gerontological Research.
9 Our center focuses on improving quality of
10 life for persons with long-term care needs.
11 I also do clinical work in the Veterans
12 Administration and research in the VA and am
13 at the RAND Corporation.

14 MEMBER LOEB: I'm Sherri Loeb. I
15 am a patient engagement strategist for EMMI
16 Solutions, which Jim is familiar with. It's
17 an outcome-based patient engagement company.
18 I also have a lot of personal experience on
19 the true need for person and family-centered
20 care after losing my husband nine months ago
21 and the lack of person and family-centered
22 care and patient engagement that we saw. So

1 I'm thrilled to be on the Committee and
2 hopefully we can come up with some true
3 measures that can be implemented and can
4 really affect the patient and be used to help
5 them.

6 MEMBER MORRISE: My name is Lisa
7 Morrise and I'm from Salt Lake City. I'm a
8 patient and family advocate. My daughter was
9 born 21 years ago unable to breathe or
10 swallow, so we've had significant numbers of
11 encounters with the system at hospitals in
12 more than just Utah.

13 And I became involved first on the
14 Patient and Family Advisory Council at our
15 local Children's Hospital and then more and
16 more involved nationally. And I currently
17 serve as the patient co-lead on the National
18 Partnership for Patients, Patient and Family
19 Engagement Affinity Group and specialize in
20 engaging patient advisors and developing
21 patient and family advisory councils that are
22 significant collaborators with their

1 facilities.

2 And I, too, am so excited about
3 these measures. And reading them, realizing
4 that some may need a little more tweaking, but
5 really appreciate the efforts to engage
6 families and patients in this way. Thank you.

7 MEMBER PARISI: Good morning. My
8 name is Len Parisi. I am vice-president of
9 Quality Management at MJHS in New York. It's
10 a post-acute care provider. We have home
11 health, hospice, palliative care, skilled
12 nursing facilities and Medicare Advantage
13 Plan.

14 I am very involved in a lot of
15 these measures. I oversee the implementation
16 and initiatives surrounding them. I'm also
17 the president of the National Association for
18 Health Care Quality.

19 MEMBER LINDBERG: Good morning.
20 My name is Brian Lindberg. I'm with the
21 Consumer Coalition for Quality Health Care.
22 I and the coalition have a long history with

1 NQF starting back when I served on the
2 original committee that Vice-President Gore
3 created to create NQF. And I've served on the
4 board and the Consumer Council off and on
5 since.

6 In addition to the work I do with
7 the Consumer Coalition, I work for small non-
8 profits in health, aging and long-term care
9 areas here in D.C. And before I started doing
10 that I spent 10 years on the House and Senate
11 Aging Committees.

12 MEMBER LEVINE: Hi, I'm Carol
13 Levine. I direct the Families and Health Care
14 Project at the United Hospital Fund in New
15 York, and the fund is a non-profit, non-
16 partisan health services research
17 organization. I, too, have a lot of personal
18 experience in this field having taken care of
19 my disabled husband for 17 years at home
20 without any person or family-centered
21 involvement, and I have a granddaughter who is
22 severely disabled.

1 But at the moment my biggest
2 problem is I need some tech help to get onto
3 the Web site. I'm technologically challenged.
4 So anyone who can send for a person who
5 understands why I can't get onto the Web site,
6 any Web site, would be helpful. Thank you.

7 MEMBER STILLE: Good morning. My
8 name is Chris Stille. I'm a professor of
9 pediatrics and head of general pediatrics at
10 the University of Colorado, also Children's
11 Hospital-Colorado, and most of my academic
12 work has centered around improving systems of
13 care for children and families with special
14 health care needs, specifically how families,
15 primary care providers and specialty providers
16 can work together to create the best outcomes.

17 And I'm happy to be here. I have
18 no conflicts of interest and the only bias I
19 would say I have is that anything that helps
20 children and families I'm biased for.

21 MEMBER VAN ZYL: Good morning,
22 everyone. My name is Carin van Zyl. I

1 originally started in emergency medicine, but
2 came to the dark side on hospice and
3 palliative care. And I am with City of Hope
4 over in Los Angeles where I'm the director of
5 quality. I have no conflicts to disclose.

6 MEMBER LEVINE: Oh, I didn't say
7 that. I have no conflicts either.

8 MEMBER NEUWIRTH: Good morning,
9 everyone. I'm Estee Neuwirth. I'm director
10 of evaluation at Kaiser Permanente's Care
11 Management Institute. I specialize in
12 spreading both qualitative and quantitative
13 methods for better understanding our patients
14 and our staff to improve quality across our
15 whole system. I'm a sociologist by training,
16 and like probably some of you, I have some
17 deep personal experiences. My mom died of a
18 hospital-acquired infection about four months
19 ago and I'm now caring for an aged parent as
20 well. So a lot of these measures touch really
21 close to home. And at Kaiser Permanente we're
22 doing our best, like many of you, to spread

1 different ways to involve patients and
2 families, and our group at the Care Management
3 Institute is leading much of that work. Thank
4 you. And I have no conflict of interest.

5 MEMBER DOWDING: Good morning. My
6 name is Dawn Dowding. I'm a professor of
7 nursing at Columbia University School of
8 Nursing and the Visiting Nurse Service of New
9 York, which is the largest not-for-profit home
10 care provider in the U.S., I think still, just
11 about. And we have home care/hospice family
12 and nurse partnerships, behavioral health
13 programs and we've got a big interest in
14 looking at patient experience and how we can
15 better improve that for our patients that we
16 care for. And I've only been here less than
17 a year, so be gentle with me. I'm still
18 getting to grips with the U.S. health care
19 system.

20 MEMBER BEVANS: Good morning. I'm
21 Katherine Bevans, an assistant professor at
22 the University of Pennsylvania's School of

1 Medicine and the Children's Hospital-
2 Philadelphia. I'm a researcher. My research
3 interest is in the development of patient and
4 family-centered methods for integration into
5 research. I have done quite a bit of work on
6 the development on patient-reported outcomes
7 for parents and especially by child-report as
8 well. I also head up the research arm of our
9 Family Partners Program at CHOP, which does a
10 lot of work on quality improvement, operations
11 of the hospital, as well as some of the
12 research initiatives as well. I don't think
13 I have conflicts of interest except to say
14 that I am also biased toward children and
15 families, as I've heard a lot of people say.
16 So thanks.

17 MEMBER THOMAS: Good morning. I'm
18 Peter Thomas and I'm with Power Pyles Sutter
19 & Verville, which is a health care law firm
20 right here a couple of blocks away, and I've
21 been there since 1992.

22 I have 40 years of experience

1 walking on two artificial limbs, and that got
2 me into health care. And when I went to law
3 school, that's what I decided to focus on. So
4 I do a lot of work in rehabilitation and
5 disability issues, all focused on health care.
6 And I don't believe I have any conflicts, but
7 I do represent a fair amount of organizations
8 and associations that are involved in this
9 general space. I've never really worked on
10 specific measures before. So I'm really glad
11 to be part of this Committee and looking
12 forward to working with you.

13 DR. BURSTIN: Great. And do we
14 have any Committee Members on the telephone?

15 MS. DORIAN: We should have -- do
16 we have, let's see, either Sherry Kaplan, Liz
17 Mort or Kimly Blanton on the call?

18 (No audible response)

19 MS. DORIAN: Operator? Kathy, are
20 you there?

21 OPERATOR: No, they're not on the
22 call.

1 DR. BURSTIN: Great. Okay. So
2 we'll return to them when they're able to join
3 us. So thank you for those actually rather
4 moving disclosures. They're not usually quite
5 that moving, but thank you for that.

6 Just a couple of reminders. You
7 actually represent yourselves, not your
8 organizations who nominated you. You really
9 are here as an individual. And the first
10 question I'd have for you is do you have any
11 questions of each other about anything anybody
12 has indicated they potentially have issues
13 with or concerns about? I think the love of
14 all children, mothers and apple pie we're
15 probably all good with.

16 (No audible response)

17 DR. BURSTIN: Great. And just
18 lastly, at any time during this process if you
19 have any concerns that there appears to be
20 something that wasn't disclosed or a bias at
21 any time, please come forward to NQF staff or
22 the chairs. We really want to take the

1 opportunity to address those in real time
2 rather than have them sort of fester and have
3 issues come out later. So again, thank you
4 for your service. Really glad this is a
5 standing committee. I think you guys will be
6 a great team together for the next few years.

7 So with that, I'll turn it back
8 over to Lauralei.

9 MS. DORIAN: Great. Thank you,
10 Helen. And thanks, everyone.

11 Now if you can go to the next
12 slide, I'm just going to go over some
13 information about your roles, the roles of the
14 developers and some ground rules.

15 As Helen just mentioned, you're
16 acting here as individual representatives for
17 the NQF multi-stakeholder group. You will be
18 serving either two or three-year terms, and
19 these terms will be selected at random. We're
20 going to be doing them tomorrow afternoon.
21 But if you have any objections to serving a
22 three-year term, please let me or one of my

1 fellow colleagues know during lunch or one of
2 the breaks today.

3 You will review all of the
4 measures. Even though we did have you
5 assigned to specific parts of measures, we'll
6 expect that you've reviewed all of them and
7 will participate in the discussion today
8 evaluating each of the measures against the
9 criteria. You will make recommendations to
10 the NQF Membership for endorsement, respond to
11 comments submitted during a review period.
12 And those can be sort of ad hoc comments that
13 occur at any time, but we also have a
14 dedicated public and member comment process
15 that will occur following this meeting. And
16 we'll go into a little bit more detail about
17 that when we review next steps tomorrow.

18 You will respond to any directions
19 from the CSAC, which is our Consensus
20 Standards Approval Committee, and you will
21 oversee the entire portfolio of person and
22 family-centered care measures. So as we

1 touched upon, this is a big change because we
2 are moving to standing committees. So we're
3 looking forward to that and getting to know
4 you.

5 And if you could go to the next
6 slide, this is just some details about that
7 change, the new function. You'll be providing
8 input on relevant measurement frameworks. And
9 we do have a number of similar projects that
10 are occurring, or relevant projects that are
11 occurring at NQF. And Karen will touch upon
12 one of those later today.

13 You'll know which measures are
14 included in the portfolio; we'll go over those
15 in a little bit of detail later, consider
16 issues of measure standardization, identify
17 measurement gaps in the portfolio, be aware of
18 other NQF activities that are related to this
19 topic area open to any external input, and
20 provide feedback continuously about how the
21 portfolio should evolve.

22 So some ground rules for today's

1 meeting. We are hoping that you're prepared
2 having reviewed the measures beforehand, and
3 we hope that some of that extra guidance that
4 we sent you you found helpful. You'll base
5 your evaluations and recommendations on the
6 evaluation criteria which we'll be reviewing.
7 Especially when we go over the first measure
8 we'll make sure you understand how to apply
9 all of the criteria.

10 We hope that you remain engaged in
11 the discussion, keep your comments concise and
12 avoid dominating a discussion. You can
13 indicate agreement without repeating what has
14 already been said.

15 And one thing I forgot to note
16 actually earlier that usually works well for
17 us is to turn your cards on their end if you
18 have a comment to make, and then we can make
19 sure to call on you and to make sure
20 everybody's heard.

21 And we did want to note that all
22 Committee Members, Co-Chairs, NQF staff and

1 developers are responsible for ensuring that
2 the work is completed in the time allotted, so
3 make sure to stick to the agenda as closely as
4 possible.

5 We are fortunate to have measure
6 developers either here with us in the room or
7 over the phone. They will be asked to briefly
8 introduce their measures in two or three
9 minutes before each measure discussion occurs.
10 They have designated places at the main table.
11 And during the measure evaluation Committee
12 Members can offer suggestions for improvement,
13 but we do want -- and sometimes the developers
14 will agree and say that they'll make changes
15 to their measures, but we do want to remind
16 you that the suggestions are only sort of
17 considered for future, but the votes that
18 you're making are on the measure as currently
19 specified.

20 And as is the case with Committee
21 Members, developers, as they sit up here, can
22 put up their cards to indicate that they wish

1 to respond to a comment.

2 So, now we're going to go over
3 portfolio review. And I think at this point
4 I turn it over to Karen.

5 DR. PACE: Okay. So the way we
6 assign these measures; and I'll get into that
7 a little bit, but currently we had 55 endorsed
8 measures that were related to person and
9 family-centered care, and 12 of the measures
10 are actually being reviewed in this Phase 1
11 that you've all seen. Eleven of them were
12 previously endorsed, so they're under
13 endorsement maintenance review. And then
14 there's one new measure.

15 Next slide. So the measures --
16 these are not the slides that I sent. They
17 don't have the measure numbers. So these are
18 the measures that are in this current project,
19 and we'll be going through them in detail, but
20 we have some from the acute care facility with
21 HCAHPS. Child HCAHPS is the new one. Three-
22 item care transition measure, inpatient

1 customer service, evaluation of inpatient
2 behavioral health services, and then the
3 clinician CAHPS.

4 Next slide. So we have the health
5 plan CAHPS. We have three measures in the
6 area of hospice and palliative care. We'll be
7 starting with those when we start into our
8 measure review. One is specifically about
9 hospice care. The other two are with bereaved
10 families that do not have -- have been in
11 hospice care. We have two post-acute
12 measures, the CAHPS in-center hemodialysis
13 survey and the home health care survey
14 measures.

15 Next slide. So one of the things
16 that we wanted to discuss is that it does
17 incorporate right now the measures in this
18 portfolio patient-reported outcomes. And this
19 is something that we'll be discussing a little
20 bit further, because these measure assignments
21 were made prior to some work that was done
22 with our HHS partners in terms of categorizing

1 performance measures based on the National
2 Quality Strategy priority and also prior to
3 some work that we've recently done with person
4 and family-centered care.

5 So I'll just mention here that
6 patient-reported outcome refers to the concept
7 of any report of the status of a patient's
8 health condition that comes directly from the
9 patient without interpretation of the
10 patient's response by a clinician or anyone
11 else.

12 In our PRO project a couple years
13 ago we adopted this definition from the FDA,
14 but we identified specifically four domains
15 that we would categorize in this area of
16 patient-reported outcomes. One is health-
17 related quality of life, which also includes
18 functional status; symptom and symptom burden
19 experience with care, which is really the
20 focus of the measures that we're looking at in
21 Phase 1 of this project; and then health-
22 related behaviors, such as smoking, diet,

1 etcetera.

2 Next slide. And this just makes a
3 distinction between -- for some terminology
4 for us to use. So patient-reported outcome
5 really refers to the concept. What is it that
6 we're thinking about measuring? PROM, or
7 patient-reported outcome measure, is
8 terminology that's often used for the patient-
9 level scale or instrument. So in this case
10 the patient-level survey questions or scales
11 that are done at the patient level. And the
12 PRO-PM or patient-reported outcome performance
13 measure is when that patient-level data is
14 aggregated up to look at how an organization
15 is doing. So we may have a facility hospice-
16 level measure, a hospital, nursing home, home
17 health, etcetera.

18 An example here is some measures
19 we have about depression. So if we think
20 about the symptom of depression, that is
21 something that is generally patient-reported.
22 We have an instrument called the PHQ-9 that is

1 widely used, and it's a nine-item instrument
2 that asks patients questions which they
3 respond to in which you can quantify their
4 level of depression. And then from the
5 performance measure standpoint we have
6 endorsed a performance measure that's -- so if
7 you talk about a hospital or a clinician, the
8 percentage of patients with a diagnosis of
9 measured depression, an initial PHQ-9 score
10 greater than 9 after follow-up, after
11 treatment, actually has a decrease in their
12 depression symptoms.

13 So the idea is that the concept is
14 depression. Then we have a very specific
15 instrument to measure a patient's level of
16 depression and then we have a performance
17 measure for the treating facility or clinician
18 that aggregates the information for all their
19 patients with depression to see how well
20 they're achieving remission of depression
21 symptoms.

22 Next slide. So experience with

1 care performance measures.

2 So, Lauralei, these are not the
3 slides.

4 Okay. Before I get onto this,
5 I'll just kind of tell you a few things that
6 I wanted to add to this. In addition to the
7 PRO project that I was referring to we also
8 recently had a project about person and
9 family-centered care and performance measure
10 framework. So in this project the goal was to
11 identify the basic concepts involved in person
12 and family-centered care. The reason I want
13 to bring this up is that in that project there
14 was a distinction made as well as the work
15 we've done with HHS about how to tag measures
16 as being in the person/family-centered domain
17 -- is that a patient-reported outcome is not
18 necessarily an indication by itself of person
19 and family-centered care. So this is
20 something we're going to want to discuss with
21 you tomorrow, but I'll give you the example.

22 What we've talked about is using

1 person and family-centered patient-reported
2 outcome measures or tools is certainly an
3 indication of person-centered care. So asking
4 the person directly about their symptoms,
5 their function is great in terms of
6 facilitating person-centered care, but if we
7 aggregate that say percent of patients with
8 remission of their depression or percentage of
9 patients that have an improved function after
10 hip surgery, that could -- may be better an
11 indicator of the effectiveness of their
12 treatment.

13 So there's some gray area about
14 where we should classify those measures and
15 how they would best be -- what steering
16 committee, what standing committee should best
17 be reviewing those types of measures. So all
18 of these things are -- there's kind of a gray
19 area and we sometimes have to make some
20 arbitrary decisions about where we place
21 measures in terms of review for endorsement,
22 etcetera.

1 Okay. There we go. Okay. That's
2 it. So this is the definition that we came up
3 with in the person and family-centered care
4 project, which is an approach to the planning
5 and delivery of care across settings and time
6 that is centered around collaborative
7 partnerships among individuals and their
8 defined family and providers of care. It
9 supports health and well-being by being
10 consistent with, respectful of, and responsive
11 to an individual's priorities, goals, needs
12 and values.

13 Okay. Next slide. So during this
14 project we came up with some core concepts;
15 and I know you can't read this here, and I'll
16 read it out to you, in terms of what are the
17 core concepts of person and family-centered
18 care?

19 So the first one is individualized
20 care. And we kind of discussed that -- or the
21 concept is that I work with other members of
22 my care team so that my needs, priorities and

1 goals for my physical, mental, spiritual and
2 social health guide my care.

3 The second concept is family. My
4 family is supported and involved in my care as
5 I choose. Respect, dignity and compassion are
6 always present. Information sharing and
7 community. There is open sharing of
8 information with me, my family and all of the
9 members of my care teams. Shared decision
10 making. I am helped to understand my choices
11 and I make decisions with my care team to the
12 extent I want or am able. Self-management.
13 I am prepared and supported to care for myself
14 to the extent I am able. And access to care
15 convenience. I can obtain care and
16 information and reach my care team when I need
17 and how I prefer.

18 So a lot of these things are
19 definitely going to be represented in the
20 experience with care measures, a lot of these
21 concepts. Some of them are not, and that was
22 part of the work of the recent measure gap

1 project in which we were looking at this
2 particular framework in terms of moving
3 forward and filling measure gaps for person
4 and family-centered care.

5 So I just wanted to kind of set
6 this up because we want to have a discussion
7 with you tomorrow; hopefully time will allow,
8 that we can get some of your thought for the
9 future of where we should be thinking of
10 assigning these measures to this standing
11 committee. So, for example, if we have a
12 performance measure about pain management and
13 pain control, is that best here or is that
14 best in a standing committee that's focused on
15 perhaps a particular clinical topic? And so
16 we'll have more discussions about that.

17 Lee?

18 CO-CHAIR PARTRIDGE: Karen,
19 sometimes in the past I know it's been NQF
20 policy to assign a measure such as the pain
21 example you just gave to two committees. Are
22 we trying to minimize that in the future?

1 DR. BURSTIN: It would be optimal
2 to keep portfolios together, but we recognize
3 at times you're going to want a consultation
4 from another committee. And that's fine. So
5 for example, our Cost and Resource Use
6 Standing Committee just recently got
7 consultation from our Cardiovascular Committee
8 on all the heart-related cost measures.
9 That's perfectly appropriate. We'd like to
10 have measures have a home and have more of a
11 consultative model as needed.

12 DR. PACE: And one of the things
13 we may have to distinguish is a measure that
14 has more cross-cutting applications, such as
15 pain versus something that's a very specific
16 -- for example, improvement in function after
17 hip surgery might be most appropriate in the
18 clinical topic area where they're talking
19 about orthopedic conditions, etcetera, versus
20 a more general functional status measure might
21 be more appropriate in this standing
22 committee. So we'll have to get some of your

1 thoughts as we're moving through this, whether
2 there are individual measures that maybe
3 should be moved in the future.

4 Okay. Next slide. So just a
5 couple other notes about experience with care
6 measures that were not submitted in Phase 1.

7 Lauralei, do you want to --

8 MS. DORIAN: Sure, so we have a
9 number of measures. Some of them are up for
10 review in Phase 2, some -- as you see on your
11 screen, a number of CAHPS measures were not
12 submitted to this current phase. We did have
13 one measure, an NCQA, it was a supplemental
14 items for CAHPS adult questionnaire that was
15 actually withdrawn because they're currently
16 in the process of finalizing revisions to the
17 shared decision making and coordination of
18 care questions that are contained within it.
19 So you can see these other measures on your
20 screen. I won't go through -- read out each
21 of them.

22 If we go to the next slide, you

1 can see some more just so you're familiar with
2 the rest of the portfolio. We have the
3 nursing home survey, the cultural competence
4 and literacy practices, and then the surgical
5 care, which we're anticipating to come in
6 Phase 2.

7 DR. PACE: And was there some
8 other ones that we know are coming in Phase 2
9 out of this list?

10 MS. DORIAN: Of -- we --

11 DR. PACE: That young adult
12 survey.

13 MS. DORIAN: The patient
14 activation measure.

15 DR. PACE: No, that's not already
16 endorsed.

17 MS. DORIAN: No, I don't --

18 DR. PACE: Okay.

19 MS. DORIAN: No, no, we don't.

20 DR. PACE: So the question will be
21 what will happen with these measures that were
22 not submitted for endorsement maintenance.

1 And that's something that NQF will have to
2 discuss with the measure developers.
3 Obviously, it would have to be consistent with
4 our policies for all performance measures.
5 Sometimes the developer withdraws them for
6 whatever reason, as Lauralei was mentioning
7 about 007. They could potentially be
8 submitted in Phase 2 as potentially the
9 surgical CAHPS maybe or potentially remove NQF
10 endorsement. But we have to have further
11 discussions with the developers to really
12 identify where they're at with those
13 particular measures. But we're just trying to
14 make you familiar with what's in the entire
15 portfolio.

16 Okay. So we've already talked
17 about these measures that we are going to be
18 looking at.

19 Okay. I'll mention just a few key
20 points. We've talked about this on
21 orientation in each of the work group calls,
22 but just to kind of reinforce is that these

1 experience with care performance measures.

2 The survey is a data collection method, not a
3 type of performance measure.

4 NQF endorses the performance
5 measures for accountable health care entities,
6 not the survey or tool or instrument by
7 itself. So obviously the survey or instrument
8 is being used to collect the data, so it's an
9 integral part of the endorsement process. We
10 couldn't have the measures without the data
11 that is collected from the patients through
12 the survey or tool. And as I already
13 mentioned, the performance measure actually
14 aggregates the data for the patient served by
15 each health care entity.

16 NQF endorsed performance measures
17 are intended for use in both performance
18 improvement and accountability applications
19 such as public reporting and pay-for-
20 performance. And as we've already talked
21 about, experience with care is considered a
22 domain of patient-reported outcomes.

1 Next slide. These measures, as
2 you've all seen already, can be based on a
3 single item or question in a survey, or
4 multiple items or questions. For the outcome
5 measures; and we include PRO-PMs, there's an
6 exception to providing a summary of systematic
7 review and grading of a body of evidence for
8 outcome measures including these PRO-PMs. We
9 really are asking the developers to identify
10 and provide a rationale which could be based
11 on evidence, and obviously that makes it
12 stronger.

13 But the idea is is it something
14 that at least one health care structure,
15 process, intervention or service affects the
16 patient experience that's being measured?
17 So is there something that the hospital, the
18 nursing home, the home health agency, the
19 clinician can do that will really affect that
20 patient's experience on the area being
21 measured?

22 And the last bullet is something

1 that came out of our project in 2012 -- is
2 that PRO-based performance measures are
3 required to be tested at both levels, the
4 patient-level data or score on the instrument
5 and then the computed performance score for
6 the health care entity. And so you've seen in
7 the submissions or some of the additional
8 material that was submitted after the work
9 group calls that generally the performance
10 measures -- first they start with testing that
11 instrument and then as they decide how they're
12 going to aggregate that information into a
13 performance score there's testing of that
14 level of the performance measure as well.

15 Next slide. So just a couple
16 mentions of some of the overarching issues
17 that we identified and some things to keep in
18 mind for our discussion tomorrow, because
19 after we go through these measures, and
20 certainly with your experience of looking at
21 them individually and on the work group calls,
22 we really want to have some discussion with

1 you, some feedback and suggestions for going
2 forward with these types of measures in the
3 future or other PRO-based performance
4 measures.

5 But specifically with the
6 experience of care measures you've seen
7 multiple measures submitted in one form. So
8 we'd like you to kind of think about what
9 works about that and what doesn't work,
10 because in some respects it might be easier,
11 but in other respects it's more complicated,
12 and we just want to have some discussion with
13 you about that.

14 The next one is that -- and this
15 is not unique to these particular measures,
16 but sometimes information was not provided in
17 the submission form or not provided where we
18 requested. And we know that that creates some
19 confusion and difficulty to find the
20 information.

21 Lack of identification of specific
22 health care structures, process, interventions

1 or services that affect the performance
2 measure. This relates to our kind of evidence
3 criterion or exception for these measures
4 where we ask the developers to identify
5 specific things that can influence this. And
6 so, I think this is something where in most --
7 in some of the cases you'll be kind of
8 substituting your knowledge and common sense
9 about are these things that can be affected by
10 health care services?

11 One of the things that came out of
12 the prior PRO project was that for these types
13 of measures we should ask the developers to
14 identify how patients were involved in
15 identifying what's of value and meaningful to
16 them in terms of collecting patient-reported
17 measures, whether it's experience with care or
18 functional status.

19 And so we did ask for that on the
20 submission form. And I think generally we had
21 little substantive information that was
22 reported. A lot of times it was noted that

1 patients were involved in focus groups. And
2 so, one of the questions I have to the
3 steering committee to think about it is is it
4 really necessary to ask for that? Should we
5 just assume it? Is it sufficient? Should we
6 just change it to a check box that they check
7 it off? So just think about that, because
8 again it's -- we want your feedback on
9 improving the process. And if it's something
10 that really doesn't add to the evaluation,
11 then we don't want to bother developers with
12 asking for that information.

13 Testing may not have been
14 submitted for both levels. And as I
15 mentioned, that is from our most recent
16 guidance. And the two levels are the patient-
17 level instrument or scale and the computed
18 performance measure. Some of the submissions,
19 there seemed to be some lack of
20 standardization. Remember we're endorsing
21 measures as a national consensus standard, and
22 so one example here is there may have been a

1 statement "can choose to adjust or not
2 adjust." And so the question is is that
3 standardized for a national standard
4 performance measure? If people are
5 implementing it different ways, how would we
6 interpret that?

7 And then generally there was a
8 lack of information about case mix adjustment,
9 development and analysis. So there may have
10 been the final report out about which
11 variables and coefficients, but not
12 necessarily the development and testing
13 process of the case mix adjustment.

14 Okay. Sam?

15 MEMBER BIERNER: I want to ask a
16 question about that issue of case mix
17 adjustment. I note in reviewing some of the
18 measures they mention that specifically and
19 some adjust for that, but across all the
20 measures that you're following in NQF, do you
21 have a percentage or some idea of how many use
22 case mix adjustment?

1 DR. PACE: I don't have a
2 percentage. Most of the outcome measures are
3 risk -- for the clinical measures the term is
4 "risk adjustment." For these measures
5 typically it's referred to as "case mix
6 adjustment." But the question to think about
7 is if there's systematic differences by some
8 patient characteristic. If it's a clinical
9 characteristic, for example, their health
10 status, how sick they are or how complex their
11 needs are, if that's a systematic difference
12 in the outcomes achieved, then it's probably
13 something to be adjusted for. And that same
14 basic concept can apply to experience with
15 care measures. And I don't know the
16 percentage of the experience of care measures
17 that are adjusted.

18 Helen, did you want to add
19 anything.

20 DR. BURSTIN: Last count I think
21 about a third of our portfolio are outcome
22 measures, and that's -- we've really pushed

1 and wanted more and more outcomes and less and
2 less process. So we'll see more and more
3 measures that have these complex case mix/risk
4 adjustment approaches.

5 Okay. So where are we on our
6 agenda? I think we're going to wait and do
7 this when we get into our first performance
8 measure.

9 MS. DORIAN: Are there any
10 questions so far? Yes?

11 MEMBER BIERNER: So other than one
12 measure all of the measures we're looking at
13 have already been endorsed and we're looking
14 at a maintenance review. Could you just
15 explain exactly what that means?

16 DR. PACE: Yes. Thanks. We
17 should have a slide on this, but NQF has a
18 policy where all the measures in the portfolio
19 are reviewed approximately on a three-year
20 cycle. Sometimes it's a little less;
21 sometimes more, because obviously we try to
22 group measures in a project. So depending on

1 when they were initially endorsed it may have
2 been a little less than two years or more than
3 -- I mean, less than three years or more than
4 three.

5 But the idea for that is that,
6 first of all, in some cases the evidence may
7 have changed for a measure, which is not as
8 relevant for these experience with care
9 measures. We want to know that there's still
10 room for improvement, because if there's -- if
11 the performance on the measure is what may be
12 referred to as topped out, everybody's
13 performing at 95, 96, 97, 98 percent of
14 achieving the process or the outcome, then is
15 it worth the effort to continue collecting the
16 data and reporting it? So that's a key
17 consideration for maintenance.

18 And then in terms of testing, the
19 idea is that if -- especially if it -- when it
20 was initially endorsed it may have come in
21 with some very minimal pilot testing and we'd
22 like to see that it really is performing as

1 we'd like for a performance measure. There
2 may be other issues that come up. We have a
3 comment period and accept comments on measures
4 that are up for endorsement maintenance.

5 And then the other thing is that
6 NQF's criteria has evolved as the quality
7 measurement and reporting space has continued
8 to mature, and so we want to make sure that
9 measures that were endorsed three years ago
10 meet the criteria as they're currently being
11 implemented.

12 So, there's a variety of reasons
13 that we would like to see updated information
14 on all of the measures, but it is something
15 that we're going to be looking at in the
16 future of if there's more distinctions of what
17 measures. But currently it's -- every measure
18 in the portfolio is expected to go through
19 endorsement maintenance review. It's the same
20 criteria. They have to meet all of the same
21 criteria.

22 CO-CHAIR PARTRIDGE: Actually,

1 Karen, I would just one other thing on that
2 point. When you're looking at them from a
3 maintenance review perspective, I think those
4 of us who have been in that role on other
5 steering committees tend to look particularly
6 at how extensively they're used. Do we have
7 a really lovely measure that we endorsed three
8 or four or five years ago that nobody's
9 picking up, and if so, why?

10 DR. PACE: Thanks, Lee. That is a
11 key point. As I mentioned earlier, the
12 measures are intended to be used for both
13 improvement and accountability applications.
14 And several years ago we had a committee, a
15 task force that took another look at usability
16 and use, and really do expect these measures
17 to be put into accountability programs within
18 three years of endorsement and public
19 reporting within six years. So the question
20 is, as Lee said, if a measure has been
21 endorsed and not in use, the question is why?

22 Now, it doesn't mean that you have

1 to vote it down. It just means that we asked
2 them to explain it and you need to think about
3 that and is there a plan for getting into use?
4 Because all kinds of things happen. And
5 especially getting things into federal
6 programs, for example, there can be all kinds
7 of delays. But it is something to think about
8 and question.

9 CO-CHAIR PARTRIDGE: We find many
10 of them are so burdensome or expensive to
11 implement that it really wasn't practical.

12 MEMBER BEVANS: Perhaps that's
13 why, but I'm wondering whether there are more
14 new measures in -- first submission measures
15 in Phase 2. And if not, whether you have any
16 thoughts as to why maybe there are so few new
17 submissions. We're doing a lot of re-ups,
18 right, but not that many new. So, thoughts
19 about that?

20 DR. PACE: I think that's a good
21 question and certainly something that as a
22 standing committee as we kind of work together

1 over the next project and the next year can
2 you have a better grasp on what's in the
3 portfolio, what the needs are, whether there
4 is a need for new measures. So it's certainly
5 a -- I can't answer that question, but I think
6 it's an appropriate topic for the standing
7 committee to tackle.

8 DR. BURSTIN: And I'll just add,
9 these are really expensive measures to
10 develop. They're not your simple process
11 measures. They take fairly deep pockets as
12 well to develop them. And then they also are
13 pretty hard to implement. So one question
14 might be how many of these do you need? I
15 mean, are they capturing the right patients in
16 the right settings? That's really important.

17 Again, I think that's going to be
18 a critical issue back -- and frankly, one of
19 the reasons we went to standing committees is
20 we'd love you guys to actually help us push
21 the field to say these are the measures we
22 need. How do we get them into NQF? Sometimes

1 they're local pilots, or local initiatives, or
2 specialty -- or things people have come up
3 with that are really great examples of what
4 could be done, but they've not moved out of a
5 local example into a national scale. And we'd
6 love to help think about how we could bring
7 forward really promising measures used on the
8 ground that potentially others could benefit
9 from if we could bring them forward.

10 MEMBER BEVANS: Yes, I guess my
11 question is really more a charge for the
12 Committee to say maybe we should do -- think
13 about some outreach, if we really use
14 perspective we believe really needs to be
15 represented in quality measurement, then we
16 need some new measures. We need to keep that
17 flow of new measures potentially coming in, I
18 think.

19 MEMBER NEUWIRTH: I was wondering
20 if we're going to be looking at all of those
21 55 endorsed measures in patient and family-
22 centered care over the course of the next two,

1 three years. And if so, can we get more of a
2 global perspective on these 55 measures and
3 how they're distributed and how they're --
4 across the different populations, and then
5 also the use. And where are we as a nation in
6 terms of using these and so on?

7 DR. PACE: Right. So, that was
8 one of the slides that didn't get in. Let me
9 just tell you in terms of the general
10 categories. Just a second. If I can find
11 this here. Do you have it?

12 Oh, okay. So of the 55 endorsed
13 measures, 21 are in the experience with care
14 topic area. And as you know, 11 were
15 submitted in this Phase 1, plus we have one
16 new. So we showed you the list of the 10 that
17 were not submitted and that we'll have to
18 follow up with the developers on. Twenty-one
19 are in the kind of general area of function
20 and health-related quality of life.

21 Right now there are three in
22 symptom/symptom burden, and all three are

1 about pain. And then there are 10 that I just
2 kind of put in a miscellaneous area. Some of
3 them are about language and meeting the
4 patient's language needs. Some are
5 communication but from a staff survey point of
6 view. And then culture. So this is just kind
7 of big picture, the areas that those 55
8 measures are in right now that are assigned to
9 this.

10 In terms of Phase 2, we're
11 focusing on function and health-related
12 quality of life, though we may have a few
13 experience with care measures that end up
14 being looked at then. And just so you know,
15 most of the function measures; and this will
16 come into do they belong in this portfolio or
17 elsewhere, are clinician-assessed function
18 measures that we'll be looking at in Phase 2.
19 And I think there's one health-related quality
20 of life, but I believe it's a process measure.

21 So anyway, I think as we look at
22 those measures, we'll have a better sense of

1 whether they should stay in this portfolio or
2 maybe they would be better elsewhere. But
3 again, there's no kind of black and white
4 line. Sometimes measures could be assigned a
5 different -- more than one topic area and we
6 just have to make an arbitrary decision, but
7 definitely something that we'll continue to
8 discuss with all of you as we really focus
9 more on person and family-centered care and
10 what measures we really want and should be in
11 this project, in this topic.

12 MEMBER NEUWIRTH: So is there
13 another committee that looks globally across
14 these 55 measures to see where there are gaps,
15 how there is use? So is there a way we could
16 get some documentation about all -- you know,
17 in a thumbnail sketch of all 55 measures so we
18 can understand them in a more global way, but
19 also how they're being used, and if so, who's
20 using them and so on?

21 DR. PACE: Yes, I appreciate what
22 you're saying in terms of over-viewing the

1 portfolio, that that would be useful, and
2 we'll have to think about how to do that.
3 That's one of the difficulties with these
4 experience with care measures is that it's not
5 21. It's 21 times -- as you all saw, one of
6 these submissions has 18 measures in it. And
7 if you go by the measure title, you don't even
8 know what it's measuring, and that's one of
9 the reasons to have individually identified
10 measures. And so, we need to be thinking
11 about that.

12 But I think it's a good point and
13 we definitely need to think of ways to
14 represent the portfolios. This is kind of new
15 work for -- or a new area for NQF in terms of
16 starting the standing committees, but how to
17 best implement the standing committees going
18 forward, we'll continue to need your
19 suggestions. And obviously being able to get
20 a better sense of what's in the portfolio is
21 key to you helping us manage it.

22 CO-CHAIR PARTRIDGE: Estee, I also

1 think that that's a role we can help NQF
2 perform, because it's not easy sitting here
3 knowing whether or not a particular hospital
4 or community has decided to use a particular
5 measure. There sort of isn't a national
6 clearing house that says this measure is being
7 used by the following entities.

8 So as we all -- we've got a nice
9 patient-centered group here. We all are
10 representing lots of different parts of the
11 country. I think as we see some of these, or
12 maybe even parts of these measures are being
13 used in our own communities or our own
14 institutions, share it.

15 MEMBER BRADLEY: As I was
16 reviewing the measures that were sent to me
17 and kind of looking across the measures, I
18 wasn't clear. Is the assumption that all of
19 these measures are in the public domain, or
20 does that matter as we're reviewing? It seems
21 like for me it may matter in terms of burden
22 of administration, but I didn't see that

1 referenced. I think it may be in one of the
2 measures that I looked at.

3 DR. PACE: Yes, all these measures
4 are in the public domain. NQF does have a
5 policy where we can accept and endorse
6 proprietary measures, but that would be just
7 -- there's a whole process of what needs to be
8 disclosed for that. But in this case all of
9 these measures, the stewards, many of them are
10 developed and supported by federal agencies,
11 so those are public. And then the ones that
12 were developed by private organizations have
13 agreed to make them publicly available.

14 MS. DORIAN: Are there any other
15 questions about the process or anything else
16 we discussed?

17 DR. PACE: So why don't we go on
18 to the --

19 MS. DORIAN: Because we're
20 actually right on time, within one minute, to
21 move on to our consideration of our first
22 measure. And so, I think before we actually

1 do that we have -- we wanted to refresh your
2 memories with a review of the measure
3 evaluation.

4 DR. PACE: Right. Would you go
5 back to the slides, because I want to just do
6 a couple and then we'll -- so, and let me just
7 -- those of you who were having technical
8 problems, at our break our technical people
9 are going to come up. Oh. Fixed? Okay.
10 Thank you. So everybody's good? Wonderful.

11 Okay. So for those of you who are
12 going to be looking at the measure, we're
13 going to be starting with 0208, but what the
14 process we're going to follow is we will start
15 with a brief introduction by the developer.
16 I will guide discussion going through our
17 criteria much like we did on the work group
18 calls. We'll ask the assigned discussants to
19 comment on how the measures do or do not meet
20 the criteria.

21 Then we can have full committee
22 discussion and questions. And then we will

1 vote on the criterion before moving onto the
2 next one. So, we'll talk about evidence,
3 we'll see if there are any issues, and then
4 we'll ask you to vote.

5 Because there are multiple
6 measures in one submission form for most of
7 these, we'll vote for all, but I'll say that
8 any could be pulled out to be voted on
9 separately. So I know on some of the work
10 group calls there were maybe particular
11 measures that people questioned or there may
12 have been issues with, so if it's something
13 like that that you think requires -- that you
14 would vote differently on one of the 12
15 measures, then certainly raise that so we can
16 pull that out to vote on separately.

17 Okay. Next slide. So we're going
18 to start with looking at the evidence
19 criterion. And basically the reason we are
20 concerned about evidence is this is the
21 foundation of using as a quality indicator for
22 validity. And for process and structures we

1 want to make sure it is something that all
2 health care units should be implementing. So
3 again, we're implementing national standard
4 performance measures.

5 But as I mentioned earlier, for
6 outcomes and including these patient-report
7 outcomes of experience with care we really are
8 just looking for identification and rationale
9 that there is something that the health care
10 unit that's being measured and evaluated can
11 influence.

12 So now let's look at our first
13 measure, importance. And we'll start with
14 evidence for this family evaluation of hospice
15 care.

16 And before we do that, Lauralei,
17 who's going to introduce the measure?

18 MS. DORIAN: Oh, yes. Do we have
19 Carol Spence on the call, or anybody else from
20 the National Hospice and Palliative Care
21 Organization who would like to introduce this
22 measure?

1 DR. SPENCE: This is Carol.

2 MS. DORIAN: Great. Thanks,
3 Carol. Go ahead.

4 DR. PACE: Okay. Thank you. So
5 the Family Evaluation of Hospice Care, or
6 FEHC, measure has been -- we -- this is up for
7 endorsement. So the survey itself has
8 actually been in the hospice field since 2003.
9 And National Hospice and Palliative Care
10 Organization, NHPCO, has also -- goes out to
11 hospices, and it has been widely adopted. We
12 have over 2,000 hospices currently using this
13 survey and getting reporting from us that
14 includes this measure.

15 We feel that this is a caregiver
16 post-death survey, so it is designed to get
17 the caregiver's perception of the quality of
18 care that was delivered. And we do a post-
19 death survey because that gives -- has the
20 advantage of providing the overview of the
21 full episode of care. Also, both the patient
22 and the family are the unit of care for

1 hospice, so this is not a proxy survey per se.
2 In the 17 items that are included in the
3 measure there are some which include the
4 caregiver's perception of symptom management,
5 for example, but many of these questions are
6 also directed at the caregiver's direct
7 experience with the care provided by the
8 hospice to them, as well as to the patient.

9 And then just one other brief
10 comment. In the material that Karen so
11 assiduously provided in the review of the
12 measure, she did note that CMS has developed
13 a hospice survey, and just a couple words on
14 that.

15 For several years CMS, in their
16 rulemaking had mentioned family evaluation of
17 care and our survey and measure and had
18 considered using it, but then they decided to
19 go ahead and develop a Hospice CAHPS survey
20 that would join the family of CMS CAHPS
21 surveys. And Dr. Joan Teno was part of that
22 development, and we worked over all these

1 years with Dr. Teno on our measure
2 development. So the Hospice CAHPS survey
3 borrows heavily from FEHC. They have a lot in
4 common.

5 We decided to go ahead and to go
6 for endorsement maintenance on this for a
7 couple reasons. First of all, the Hospice
8 CAHPS survey is not going to be required
9 across the board for implementation until
10 April 2015 and we felt that hospices still
11 should have an endorsed survey to use up until
12 the time that they need to switch to that.

13 The other reason is that hospices
14 -- not every single hospice will be using the
15 CAHPS survey. There are eligibility
16 requirements for that. So a hospice that has
17 fewer than 50 eligibles deaths will not be
18 participating -- for the previous year will
19 not be participating in that Hospice CAHPS
20 survey. And we're not sure exactly what that
21 proportion will look like at this point, but
22 one of the eligibility criteria for Hospice

1 CAHPS is going to be that the patient had
2 received hospice services for at least 48
3 hours.

4 And we do know that a third of
5 hospice patients die within seven days or
6 less. I'm not sure what the statistic is
7 exactly on that 48 hours, but there will be
8 smaller hospices out there who will not be
9 participating in the Hospice CAHPS. And we
10 wanted them to continue to have the
11 availability of the FEHC survey if they so
12 chose to use it, because this measure has
13 definitely become very much part of hospice's
14 QAPI programs and we wanted them to have the
15 ability to continue to use it. So, thank you.

16 DR. PACE: Okay. Yes, Brian?

17 MEMBER LINDBERG: This is Brian
18 Lindberg. I just had a clarifying question
19 related to that. How will one determine which
20 of the potential two surveys that an
21 individual family would complete?

22 DR. SPENCE: Well, a hospice that

1 meets those eligibility requirements of having
2 more than the 50 deaths is going to have to
3 use the Hospice CAHPS survey. So it would be
4 again up to the hospices that don't meet those
5 eligibility requirements to decide whether
6 they want to continue to use FEHC perhaps,
7 since they're already using it, or switch over
8 to the Hospice CAHPS survey. But the public
9 reporting and the submission is only going to
10 be done by those hospices with 50 or more
11 deaths.

12 CO-CHAIR PARTRIDGE: Sherri?

13 MEMBER LOEB: This may be in here;
14 this is Sherri Loeb, and I apologize if it is.
15 Is this for any hospice care? It does not
16 need to be an inpatient hospice facility? So
17 it can be home hospice?

18 DR. SPENCE: It's all deaths.

19 MEMBER LOEB: Okay.

20 DR. SPENCE: It doesn't matter
21 what the setting or where the place of death
22 is. It doesn't matter. As you may know

1 patients sometimes change settings of care.
2 Hospice is an approach to care as opposed to
3 setting-specific. So it can be inpatient,
4 hospice inpatient. It can be someone who had
5 the majority of their care at home. So it
6 covers the entire episode of hospice care
7 regardless of setting.

8 CO-CHAIR PARTRIDGE: Thank you.
9 Debra?

10 MEMBER SALIBA: Just a couple of
11 questions. I'm Deb Saliba. One of the
12 questions is how many hospices are there in
13 the U.S.?

14 DR. SPENCE: That depends on how
15 you count hospices.

16 MEMBER SALIBA: Okay.

17 DR. SPENCE: The ones that are
18 Medicare-certified the way CMS counts them is
19 by their CMM number, but -- or the Medicare
20 provider number, but hospices can have more
21 than one site to bill under that number. So
22 when we count them, we count them by site or

1 location rather than by parent. So we have --
2 our number comes up to around a little over
3 4,000. CMS has just over 3,000. So again, it
4 depends on how you want to define a hospice.

5 MEMBER SALIBA: Because I noticed
6 that somewhere in these materials that the
7 majority of the participants were not-for-
8 profits in the survey.

9 DR. SPENCE: I don't know that
10 that is necessarily the case. It could be
11 50/50, but I don't -- I can't off the top of
12 my head -- Matthew Haskins, our analyst, is
13 also on the line.

14 Matt, do you have a number for
15 that?

16 MR. HASKINS: Yes, so the
17 utilization rates -- she's right, at the site
18 level it's a little more strongly associated
19 with -- not strongly associated, but there is
20 a little bit more not-for-profit providers
21 utilizing this survey at this point in time.
22 But, yes.

1 MEMBER SALIBA: Okay. So --

2 MR. HASKINS: And again, we're
3 talking about the site level though. We're
4 not necessarily talking about the agency
5 level.

6 MEMBER SALIBA: Ah, okay.

7 MEMBER BIERNER: It looks like it
8 says 746 not-for-profit in the specifications
9 from the developer.

10 MEMBER SALIBA: Yes, which is I
11 think a slightly higher proportion than what
12 there are nationally.

13 DR. PACE: So let's walk through
14 the criteria and then we can -- where this may
15 be relevant can discuss that.

16
17 So, our first criterion is about
18 the evidence. And basically what again what
19 we are looking for here, are there health care
20 actions that can influence this? This
21 particular survey has produced -- they're
22 submitting one performance measure that really

1 accommodates all of the major topics in the
2 survey. So, and they provided -- Nadine, will
3 you go to the -- they provided information
4 about health care actions that can influence
5 this particular experience with care.

6 So, and again, on the agenda that
7 you all have at your seat we reminded you who
8 was reviewing different aspects of this
9 measure, so those of you who were specifically
10 reviewing importance, the feasibility and use
11 and usability, that group, and anyone else --
12 but if you have any comments about or any
13 issues with the fact that the hospice unit can
14 influence experience with care on this
15 measure.

16 CO-CHAIR PARTRIDGE: Those can be
17 either pro or con.

18 DR. PACE: Right.

19 CO-CHAIR MERLINO: I'm on the
20 list, so I would add that the evidence to
21 support process improvement is pretty strong
22 with this survey.

1 DR. PACE: Any other comments?

2 (No audible response)

3 DR. PACE: So I think we will then
4 proceed to voting on this. And, we'll --

5 MS. DORIAN: Let me just check
6 before we do that to see if we have steering
7 committee members on the phone at this point.

8 (No audible response)

9 MS. DORIAN: Okay. So you all
10 should have received -- just raise your hand
11 if you don't have a voting device. Oh, you
12 don't have one?

13 MEMBER SALIBA: I just have a
14 question.

15 DR. SPENCE: Oh, sure.

16 MEMBER SALIBA: Are we going to
17 talk about the reliability and feasibility?
18 Are we just voting? We're voting section by
19 section?

20 DR. PACE: Yes. Right. Criterion
21 by -- it must pass criterion by must-past
22 criterion. So this is strictly about the

1 evidence criterion, which on these measures is
2 are there health care actions that the hospice
3 can take that will influence the experience?

4 MEMBER SALIBA: Okay.

5 MS. DORIAN: So, Nadine now will
6 review how we're going to be using these
7 voting clickers -- devices.

8 MS. ALLEN: Please point the
9 clicker towards my direction. This will be
10 the laptop that will be capturing all your
11 votes. When you click for your vote, for
12 example for evidence 1A, you can select 1 for
13 yes, 2 for no. You do not have to hit send on
14 the clicker. Just hit the number and it will
15 register. You can change your vote at any
16 time. You have 60 seconds to vote. And once
17 the 60 seconds is up, we capture that vote.
18 Any questions?

19 DR. PACE: And the voting slides
20 you'll see on the two screens at the end. So
21 in this case we're talking about that there
22 was a rationale that supports the relationship

1 of the health care outcome or PRO to at least
2 one health care structure process intervention
3 or service.

4 MEMBER VAN ZYL: You mentioned
5 that the work sheets from the group calls
6 would be available, but I cannot find them.
7 Is there any way that we can pull them up just
8 so that the rest of the Committee Members who
9 weren't on the work group know what the
10 comments about this particular section were?

11 DR. PACE: Yes, we'll have someone
12 come down and help you --

13 MEMBER VAN ZYL: Okay.

14 DR. PACE: -- pull them up.

15 MS. DORIAN: Somebody should be
16 coming up soon.

17 CO-CHAIR MERLINO: Len?

18 MEMBER PARISI: I had a question
19 about what you just said, Karen, that the
20 criteria would be that it would be actionable
21 based on the performance measure, so that
22 would be the composite score in this case?

1 DR. PACE: Okay. So in this case
2 the composite is made up of all of these
3 elements. And so, yes, that there is at least
4 one health care structure, process,
5 intervention or service that can influence the
6 overall experience that's captured by this
7 particular composite.

8 MEMBER PARISI: Would it be -- and
9 my understanding is the composite score in
10 itself would not be actionable. You'd have to
11 do a drill down. So is that what you're --
12 also mean?

13 DR. PACE: Yes, that -- so it's
14 not that the composite score will tell you
15 what to do, but there are things that you --
16 based on what's included in that composite
17 score you can drill down and look at your own
18 care and find out what you can do. And that's
19 not just an issue with experience with care
20 PROs, but with outcome measures in general.
21 So say you were doing a measure of mortality.
22 That outcome measure itself doesn't tell the

1 hospital or home health agency what they have
2 to do. They would have to drill down and look
3 at their care processes to see if their
4 patients who die versus the patients who
5 survive -- there are different things that
6 they should be doing.

7 So it's really about -- not so
8 much that they would have to drill down, but
9 are the things that are being captured in this
10 composite actionable? Are there at least some
11 things that will be influenced by the hospice?

12 MEMBER PARISI: Just one last
13 question. The issue of the language, the
14 translation of the instrument, I had raised
15 that during our work group call, and where
16 does that figure into this? According to the
17 documentation here it says it's only in
18 English. I know that CAHPS will be required
19 to be in multiple languages, so there will be
20 some discrepancy there.

21 DR. PACE: It's a good point.
22 Yes, let me think about that. It won't be

1 here in evidence though, but I'll give that
2 some thought.

3 And just one comment about the
4 fact that there will be a Hospice CAHPS. It
5 really shouldn't influence how we vote on
6 this, how you evaluate this measure. In the
7 future when Hospice CAHPS comes to this
8 Committee for endorsement, then you'll need to
9 be thinking about that would be a competing
10 hospice to this one and which one would be the
11 better one for NQF to endorse?

12 But I think that -- the language
13 issue I believe we should probably think about
14 under validity, because if it's knocking out
15 a big portion of the population -- we'll hold
16 that for now.

17 MEMBER MORRISE: I was wondering;
18 and maybe the person who is on the telephone
19 could share, was this a measure only for
20 family members of patients who were 18-plus,
21 or did it include pediatric patients who may
22 have been in hospice care and their bereaved

1 family members?

2 DR. SPENCE: This is Carol. It
3 does not include pediatric, you are correct.
4 This is for patients who are 18 years and
5 older.

6 CO-CHAIR MERLINO: Debra?

7 MEMBER SALIBA: So, just two
8 questions: Can this be endorsed in a time-
9 limited way? Can we say that it's endorsed
10 through 2015 or 2016 so that it could be
11 reconsidered with the CAHPS hospice?

12 DR. PACE: No, we don't do time-
13 limited endorsements.

14 MEMBER SALIBA: Okay.

15 DR. PACE: So it would be endorsed
16 until such time that a Hospice CAHPS would be
17 brought to NQF to be considered for
18 endorsement.

19 DR. BURSTIN: So at that time the
20 measure would be endorsed for three years, but
21 at the time a new measure comes forward that's
22 competing against it, they will have an

1 opportunity to look at them together.

2 MEMBER SALIBA: Effectively it is
3 sort of time -- when another competing measure
4 comes up?

5 DR. BURSTIN: We don't use that
6 term just because it is truly endorsed for a
7 three-year term, but we will make sure there's
8 an opportunity to look at them side-by-side as
9 the new measure comes forward.

10 MEMBER SALIBA: So the other
11 question that I had was -- gets to the issue
12 of actionability. I thought it was somewhat
13 striking that the average composite scores
14 over the past three years have really not
15 increased. I mean, it's a statistically
16 significant increase, but it's basically the
17 same. It goes from 85.37 percent to 85.51
18 percent. It's an average. So it could be
19 that there were some facilities that improved
20 and some that didn't.

21 I don't know if the developers
22 have some insights about anything breaking

1 down more at the organizational level as
2 opposed to this mean, because this would tell
3 me that it would not be that actionable
4 because we're not seeing the scores move very
5 much over three years.

6 MR. HASKINS: I can comment on
7 that; this is Matthew Haskins with NHPCO, if
8 you want me to at this stage. Or if you want
9 me to hold it to another stage I can as well.

10 DR. PACE: Go ahead, Matthew.

11 MR. HASKINS: Okay. So we've been
12 internally looking at that number recently,
13 actually before NQF submission started, but
14 what you're seeing there is a lot of
15 organizations coming in to and out of the use
16 of FEHC. It's actually more coming into the
17 use of FEHC. So the average change gets
18 diluted when you get all these folks that have
19 started using FEHC for the first time.

20 When you look at organizations
21 that have utilized FEHC continuously, over a
22 period of time you actually start to see more

1 improvement on those FEHC scores.

2 MEMBER SALIBA: Thank you. That's
3 really helpful.

4 DR. SPENCE: Thank you.

5 MR. HASKINS: You're welcome.

6 MEMBER THOMAS: I have two quick
7 questions, hopefully. The first is that if
8 we're going to be voting on each one of these
9 very individually, there's -- maybe not with
10 respect to this particular vote we're about to
11 take, but there are a number of instances that
12 I reviewed very much depth where the data
13 won't be in the right place, it won't be
14 submitted, but it might be in some attachment
15 or something and that's noted. The case may
16 not have been well made and yet it still is
17 viewed as highly or moderately appropriate
18 kind of evidence. And so I'm grappling with
19 what to do with that, number one.

20 And number two, what are the
21 consequences of this vote? A, I assume this
22 is majority rule, but I don't know that. And,

1 B, if there is a failure of one of these must-
2 pass elements, then what actually happens to
3 that measure? What's the consequence?

4 DR. PACE: So, Nadine, will you go
5 back to the beginning of the slides so we can
6 review? No, go back to the -- okay.

7 So good question. So thank you
8 for kind of making us pause here. So the
9 must-pass criteria, which are all of those
10 under importance: evidence, performance gap,
11 priority and then reliability and validity --
12 each one of those is a must-pass criterion,
13 meaning if it doesn't pass, then we stop. It
14 doesn't go forward. However, this year it's
15 not just a simple majority. We've instituted
16 a process where if it's in the 40 to 60
17 percent range, then we continue on because we
18 consider that not sufficient consensus to say
19 it should stop or affirmatively move forward.

20 So we will be during the voting
21 identifying the percentage and anything that's
22 in the 40 to 60 percent range you'll continue

1 to vote. If it were less than 40 percent that
2 says it met the criteria, it would stop. So
3 that's kind of where we're at with the voting.

4 Now, in --

5 CO-CHAIR PARTRIDGE: Karen?

6 DR. PACE: Yes, go ahead.

7 CO-CHAIR PARTRIDGE: Forty to
8 sixty percent of those of us who are at the
9 meeting or absolute number?

10 DR. PACE: Right. We need a 75
11 percent quorum, so we are right at 75 percent.

12 MS. DORIAN: Right. And we don't
13 actually currently have anybody on the phone
14 right now who will be voting, so it is limited
15 to the 17 who are in the room.

16 CO-CHAIR PARTRIDGE: Okay.

17 DR. PACE: So good questions. I'm
18 glad you're bringing these up. And I should
19 also mention that it's -- in terms of passing,
20 a moderate or high get combined. So moderate
21 is passing. High is passing. Low is not.
22 And insufficient information to determine

1 whether it meets the criteria also would be
2 not passing.

3 So your next question is if you
4 think they haven't made the case, there's a
5 couple things: One is if it's clearly that it
6 -- let's take reliability. If what they
7 submitted demonstrates it's not reliable
8 enough, then you would vote low. If you feel
9 that they haven't submitted the information
10 for you to tell whether it's sufficient
11 reliability or not, then you would vote
12 insufficient. Essentially, they have the same
13 effect, but it's more clear what the issue is.

14 And if it's insufficient
15 information, for example, the developer might,
16 during the comment, period be able to provide
17 additional information or tell us about it
18 today on the phone. That would kind of be
19 able to fill that gap so that when you re-look
20 at these after the comment period that it
21 might change what you thought about it.

22 Katherine?

1 MEMBER BEVANS: This is a question
2 for the developer. Are we ready to get back
3 to that or --

4 DR. PACE: Is it about evidence?

5 MEMBER BEVANS: It is about
6 evidence.

7 DR. PACE: Okay.

8 MEMBER BEVANS: With regard to the
9 importance of the five dimensions that are
10 identified for quality, could you comment on
11 how if at all patients or care providers were
12 involved in the selection of that content or
13 the prioritization of that content?

14 DR. SPENCE: You're talking about
15 the domains that the group --

16 MEMBER BEVANS: Yes.

17 DR. SPENCE: Those were not a
18 priori. Those were based on factor analysis.

19 MEMBER BEVANS: Well, when you
20 originally developed the measure you generated
21 a number of items. How was the content of
22 those items determined initially?

1 DR. TENO: Oh, so maybe I --

2 DR. SPENCE: Go ahead, Joan.

3 DR. TENO: -- can answer.

4 DR. SPENCE: Go ahead.

5 DR. TENO: Yes. Hi, Joan Teno.

6 I'm a little bit jet lagged because I just got
7 back from California late last night, but we
8 assembled an expert panel. We did focus
9 groups with bereaved family members that have
10 a published paper and we published a
11 conceptional model. Prior to that we also
12 worked with Anita Stewart to develop an
13 overall conception model that's based on a
14 Donabedian model. So we started out with an
15 overall conception model based on a Donabedian
16 model. Then we did expert panel, focus groups
17 and then took the items back to the expert
18 panel and had them do a ranking thing which
19 was under the control of the hospice. And
20 much of this has been published in JPSM.

21 In development of the second
22 version instrument, when they looked at the

1 core with the expert panel again, we had them
2 do another ranking procedure where they said
3 the degree to which it was under their
4 control, it's important. We also just
5 recently have completed and have our first
6 article published on focus groups with
7 bereaved family members again. And again, we
8 did a total of 16 focus groups from 5 regions
9 across the country. And again, they
10 reaffirmed sort of this core contents area.

11 DR. PACE: Okay. And let me just
12 say that that's a question that we address
13 under high priority, how the patients were
14 involved. So right now we're voting on the
15 question whether there are health care
16 interventions and actions that can influence
17 the patient's hospice experience as captured
18 in this measure.

19 CO-CHAIR PARTRIDGE: And we are
20 about to vote. Everybody ready?

21 (No audible response)

22 CO-CHAIR PARTRIDGE: Okay.

1 DR. PACE: Wait a minute. Nadine,
2 you need to go to the right voting slide.
3 Okay.

4 All right. So one is yes, two is
5 no.

6 Oh, so, let me just wait until --
7 you'll see in the lower right-hand corner when
8 the timer starts. It will count down. So
9 just give us a moment.

10 MS. DORIAN: So you can begin
11 voting now.

12 (Voting)

13 That's 16 yes, and 1 no.

14 DR. PACE: Okay. Let's move on to
15 then the next question, which is performance
16 gap. And here we want you to discuss does the
17 performance data provide a demonstrated gap in
18 care, which can be variability or overall less
19 than optimal performance to warrant a national
20 performance measure? Does the performance
21 data provided demonstrate disparities for
22 certain population sub-groups?

1 So this is where we ask them to
2 provide some information about performance on
3 the measure, and it can -- a performance gap
4 can either be on the facility performance or
5 disparities in care that would warrant us --
6 that there's opportunities for improvement.

7 So for those of you who looked at
8 importance, Carol, Brian, Sherri Loeb, Jim and
9 Carin, any thoughts about performance gap?

10 MEMBER LOEB: I definitely think
11 there's a performance gap and I think this is
12 just crucial to helping to eliminate that
13 performance gap having some standardization.

14 CO-CHAIR PARTRIDGE: And this is
15 Lee. I would just add that I thought that the
16 answer to Debra's earlier question about the
17 trends and fact that the more -- that those
18 that have been using this survey longer do
19 demonstrate some improvement. But the newer
20 users are discovering that they have issues to
21 address probably also reinforces Sherri's
22 position.

1 Are we ready to vote?

2 DR. PACE: Right. And let me just
3 mention, those of you who may not have taken
4 the deeper dive on these measures, if you have
5 questions for your colleagues that did,
6 definitely bring them up as well.

7 Oh, on this particular -- we ask
8 you to rate high, moderate, low or
9 insufficient information to rate it. So it
10 may be that if it didn't look like there was
11 wide gap, you might want to vote moderate. If
12 it looked like a large gap, high, and so
13 forth. So any questions about voting before
14 we start?

15 (No audible response)

16 MS. ALLEN: So one is high, two
17 moderate, three low and four insufficient.
18 We're ready to start voting.

19 So 6 high, 11 moderate, no low and
20 no insufficient.

21 DR. PACE: Okay. So now we'll
22 move onto 1C, which is high priority. And I

1 think the key issue here obviously is that
2 it's an important area in terms of numbers of
3 patients and consequences of quality, but the
4 thing that's specific -- the other issue
5 specific to PRO performance measures is how it
6 was determined that the target population
7 values each individual measure focus and finds
8 it meaningful.

9 So in this case I think we heard a
10 little bit about that.

11 MEMBER BEVANS: Just a follow-up
12 question. Sorry to pose that question at the
13 wrong time before, but in the identification
14 of these concepts you mentioned your expert
15 panel. Could you describe the panel? Who was
16 that made up of?

17 DR. PACE: Carol or Joan, could
18 you describe the focus groups?

19 DR. SPENCE: I mean, I can answer,
20 but Joan actually did that work, so it would
21 probably be better if she -- Joan, are you
22 there? Can you --

1 DR. TENO: Yes. No, I'm sorry.
2 I'm just muting myself and my iPhone thumb was
3 not doing well, so I had to put in the number.

4 So we included experts from
5 nursing, medicine, cancer care, people who
6 were administrators in local hospices. And
7 then in the original sample, industries and
8 sample we also -- in addition to those experts
9 we also included five persons who were the
10 quality managers of their local hospice
11 quality --

12 DR. PACE: I think we're most
13 interested in the patients and families, or
14 the families.

15 DR. TENO: Oh, the patients and
16 families? Okay. I'm sorry. I thought you
17 were talking about the expert. I thought the
18 question I heard was about the experts.

19 So patients and families. So the
20 original focus groups were done throughout New
21 England dealing with bereaved family members
22 from hospice, from people who died in a

1 nursing home, and people who died in an acute-
2 care hospital and people who died at home
3 without services.

4 In the subsequent follow-up papers
5 that we're going to be publishing, one is
6 already in press, we did -- we included
7 bereaved family members from hospice, from six
8 hospice programs. We chose two of those
9 hospice programs specifically because they had
10 a high Hispanic population and one had a high
11 African-American population. And then one
12 hospice program was located in a rural
13 location. So we tried to get a geographically
14 diverse group of family members. And we also
15 tried to do separate focus groups that were
16 dependent on the levels of care. So we
17 focused on people who died in the hospice
18 inpatient unit, people who died in a nursing
19 home or assisted living facility and people
20 who died at home.

21 Does that answer your question?

22 MEMBER BEVANS: It does. A quick

1 process question: Unless I'm missing it, I
2 don't think this information is in the
3 submitted material and I'm -- should we
4 consider it in our voting of the sufficiency
5 of the evidence? Okay. Thank you.

6 DR. PACE: Yes, I think in this
7 case -- I think it's a good point and we did
8 ask for it. And that was one of the things I
9 brought up earlier. We got minimal
10 information in most of the submissions. And
11 so, it's something for you all to think about
12 for the future, whether it's something we need
13 to press harder to get or whether it's not
14 really that useful for your evaluation.

15 CO-CHAIR PARTRIDGE: Debra?

16 MEMBER SALIBA: As one of the deep
17 divers on this section, Joan, this is Deb
18 Saliba. Welcome back. We changed coasts. I
19 wanted to ask you a question about the data
20 that you're talking about right now. Is this
21 for the care instrument, or is this for the --

22 DR. TENO: No, this is -- so to

1 explain a complicated story, there has been
2 two processes that have been ongoing that I'm
3 involved in. I have an RO1 and during that
4 RO1 we looked at the core of the FEHC again,
5 the Family Evaluation of Hospice Care, and
6 then we looked for additional items. And that
7 is the project that we just did the 18 focus
8 groups on. The first paper has been published
9 from that. And then we're -- I'm currently
10 summarizing all those focus groups for my
11 report from our RO1.

12 Also, at the same time we've been
13 working on the parallel process of the Hospice
14 CAHPS tool as well. I've been involved in
15 that. So I've overlapped on sort of both
16 projects. And it's probably my fault just
17 given -- I've had somewhat of a crazy spring
18 in that my dad had a 22-day ICU stay where he
19 almost died and I probably just have not been
20 able to attend to all these issues when I've
21 been dealing with a family emergency.

22 MEMBER SALIBA: I'm sorry to hear

1 about that, Joan. I hope he's okay.

2 So I guess --

3 DR. TENO: He finally got
4 discharged yesterday. So, yes.

5 MEMBER SALIBA: Yay. Congrats.

6 DR. TENO: So, thank God.

7 MEMBER SALIBA: So my question is
8 about the care versus the FEHC. Not the
9 CAHPS. The care. So the one that actually
10 goes across multiple settings --

11 DR. TENO: Yes.

12 MEMBER SALIBA: -- that you
13 developed and published the paper in JAMA
14 about. And I know the FEHC is derivative of
15 the care, but I guess I'm sort of looking at
16 the care as one that does multiple settings
17 and would allow us to cross --

18 DR. TENO: Yes, right.

19 MEMBER SALIBA: I know we don't
20 want to skip ahead, but in a way I think it's
21 an important question about the importance,
22 because this is only looking at hospice versus

1 hospice, whereas the fundamental question may
2 be what goes on in different care settings
3 with and without hospice?

4 CO-CHAIR PARTRIDGE: But we do
5 have to focus right now on this one. We
6 understand --

7 MEMBER SALIBA: Well, I think it's
8 an important issue then that this is only
9 limited to voluntary participation --

10 CO-CHAIR PARTRIDGE: Yes.

11 MEMBER SALIBA: -- of hospices as
12 opposed to the fact that people often get end-
13 of-life care in multiple other organizations
14 and settings.

15 CO-CHAIR PARTRIDGE: Yes.

16 MEMBER SALIBA: So I think for
17 importance that's a limiting factor for this
18 particular one.

19 DR. PACE: So, yes, our priority
20 criterion is about the topic area. That gets
21 into kind of the specific measures and what
22 patients are included. So this is really

1 about is it a high-priority area and were
2 patients and -- or families involved in
3 identifying what should be measured. And then
4 under reliability and validity the
5 specifications is where we get into the
6 specific measure, so in this case limited to
7 hospice patients. But it's a good point.

8 And then if we have time, we'll
9 start talking about competing measures, which
10 we have three in this space: the care, this
11 one and the VA measure where we can talk about
12 some of the issues across them.

13 CO-CHAIR PARTRIDGE: I'm concerned
14 about keeping us on the clock, and this our
15 first measure. I think it's important to
16 discuss a lot of these issues, but Jim and I
17 are going to be a little mean as the two days
18 go on.

19 (Laughter)

20 DR. PACE: Okay. Any other
21 questions about high priority?

22 (No audible response)

1 MS. ALLEN: So we're going to
2 start voting on high priority. One meaning
3 high; two, moderate; three, low; and four,
4 insufficient. Starting the clock now.

5 (Voting)

6 MS. ALLEN: One more. Please vote
7 again.

8 (Voting)

9 MS. ALLEN: Perfect. Thank you.
10 And the results are: 11 high, 5
11 moderate, 1 low, and no insufficient.

12 DR. PACE: Okay. We're going to
13 move onto reliability and validity. So before
14 we actually talk about this particular
15 measure, I'm going to do a couple slides about
16 reliability. We'll do that first and then --
17 before we go to validity.

18 So, Nadine, can you pull those up
19 again?

20 Okay. So just a couple of points
21 about reliability and validity in general.
22 Why are we concerned about it? Again, NQF-

1 endorsed measures are intended for use in
2 accountability applications such as public
3 reporting and pay-for-performance. And the
4 scores are used to make conclusions about a
5 health care unit's quality. It could be
6 patients and consumers making conclusions,
7 health plans, purchasers and the health care
8 units themselves. And if it's not an
9 indicator of quality, it's a validity issue.
10 And if there's too much measurement error, it
11 becomes a reliability issue.

12 So, next slide. A few notes on
13 reliability. And we had this in your briefing
14 memo, but reliability is a way to quantify the
15 amount of random measurement error and how
16 well we can confidently distinguish between
17 patients when we're talking about patient-
18 level measures or between the health care
19 units when using the computed performance
20 score.

21 Low reliability means that it
22 could be difficult to distinguish between

1 patients or between the health care units and
2 could lead to misclassification. So, and then
3 reliability is not a fixed property. It can
4 vary depending on the groups included in the
5 measurement, the patients and health care
6 units.

7 Next slide. Just a couple notes.
8 I think most of you have noticed this, that
9 common testing approach for patient-level
10 scales or measures is internal consistency
11 reliability which assesses the consistency of
12 responses for items in the scale. This is
13 often measured by Cronbach's alpha, which is
14 the average intercorrelation among the items,
15 and the values range between zero and one.

16 A common testing approach for
17 single item measures is test-retest which is
18 measured by interclass correlation
19 coefficient. Again, values range between zero
20 and one for that. Or it could be a Pearson
21 correlation. And I don't know that we've seen
22 any test-retest in the submissions that we

1 received. I don't believe so.

2 And then common testing approach
3 for a performance score is signal-to-noise
4 analysis which reflects the proportion of
5 total variance that is due to the signal or
6 the real differences between units. It is
7 often measured by ICC or inter-unit
8 reliability which is based on the F test from
9 INOVA. So basically the values will range
10 between zero and one. And rule of thumb is
11 that a minimum reliability of 0.7 to 0.75 is
12 needed when you're trying to make distinctions
13 between various units.

14 So with that, we'll get into
15 discussion of the reliability information that
16 was submitted for the Family Evaluation of
17 Hospice Care. Also, the other thing that we
18 include under reliability is that the
19 specifications are precise. So I know
20 everyone looked at specifications, so if there
21 were any questions about the actual measure
22 specifications, whether there were any --

1 anything that was unclear, this would also be
2 the place to bring that up if you had any
3 questions.

4 But for this, for looking at the
5 reliability and validity, Katherine, Don,
6 Lenard, Deb Saliba, if you have anything to
7 start us off.

8 CO-CHAIR MERLINO: I would just
9 add. So one thing that Lee and I asked last
10 week, or two weeks ago, was that the NQF staff
11 really drill into reliability and validity on
12 each one of the measures recognizing that,
13 with the exception of a couple of people
14 around the room, we're not statisticians.
15 Unless you use this all the time, it can be a
16 little tricky. So the summaries that they
17 passed out really get into the issue of
18 whether it's appropriate or not and whether
19 the test results are valid.

20 MEMBER DOWDING: Yes, this is
21 probably more to do with validity than
22 reliability, but it's picking up on the point

1 of the lack of translation into Spanish. If
2 you look at the people who've responded to the
3 survey, 97 percent are white. And I think
4 there's an issue about whether or not the
5 questions that are being asked are capturing
6 diversity, because we're obviously getting a
7 vast proportion of people who are choosing to
8 reply and respond who are from a certain
9 ethnic group.

10 DR. PACE: Can you hold that
11 validity, because I think that is -- and I
12 know it came up in one of the prior questions
13 as well and I think it's something worth
14 noting there and discussing.

15 CO-CHAIR PARTRIDGE: Any other
16 comments from either the group that took the
17 deeper dive or the rest of us?

18 MR. HASKINS: This is Matthew
19 Haskins from NHPCO. I wanted to jump in on
20 that last comment about the population
21 demographic mix.

22 CO-CHAIR PARTRIDGE: Can we hold

1 that until we get to that one, please?

2 MR. HASKINS: Oh, I thought she
3 brought that up in the context of validity.

4 DR. PACE: We're trying to focus
5 on reliability right now, so we ask to hold
6 that until we talk about validity, please.

7 MR. HASKINS: Okay.

8 DR. PACE: Thank you.

9 MR. HASKINS: No problem.

10 CO-CHAIR PARTRIDGE: Ready to
11 vote?

12 DR. PACE: So does anyone else
13 have any other comments about this? They did
14 test at the patient level instrument level
15 with Cronbach's alpha and the statistics were
16 good. And then they did the signal-to-noise
17 based on INOVA and IUR, and it was 0.76 for
18 this composite. So based on our algorithms;
19 and those are also at your place, this could
20 be rated high on reliability unless you have
21 any concerns or issues. If you didn't think
22 the sample was large enough. It was done in

1 1207 hospices. Or if you had concerns about
2 the testing. But any questions before we move
3 on to voting on reliability?

4 (No audible response)

5 DR. PACE: Will you bring up the
6 reliability vote?

7 MS. DORIAN: And I'll again just
8 confirm, do we have any Committee Members on
9 the phone? Liz, are you there?

10 MEMBER MORT: I am here, yes.

11 MS. DORIAN: Well, great.
12 Welcome. Would you like to briefly introduce
13 yourself since you've just joined? We went
14 around earlier this morning. So if you just
15 wanted to say a few words about your
16 background?

17 MEMBER MORT: Yes, I apologize for
18 signing in late this morning. My name is Liz
19 Mort. I'm an internist at Mass General,
20 senior vice-president of Quality and Safety
21 and chief quality officer, and I've been
22 working in quality measurement for a couple of

1 decades and delighted to be part of this
2 panel. I apologize I could not be there in
3 person today.

4 DR. PACE: Great. Thank you. And
5 did you feel comfortable voting on this
6 measure via the chat function in the Webinar,
7 or would you prefer -- I'm not sure when you
8 joined, if you wanted to start voting in the
9 next --

10 MEMBER MORT: I'd rather start at
11 the next go-round because I came in partially
12 through the beginning -- I didn't start at the
13 beginning of this measure's presentation. I'd
14 prefer to wait until the next one, if that
15 okay with you.

16 DR. PACE: Okay. No, that's
17 perfect. Thank you. I'll send you a message
18 in the Webinar chat to make sure it's working
19 and you can receive it.

20 MEMBER MORT: Thanks.

21 DR. PACE: Okay. Nadine? Any
22 other questions about voting on reliability

1 for this measure?

2 (No audible response)

3 DR. PACE: Okay.

4 MS. ALLEN: So now we're voting on
5 reliability. Same answers: One, high; two,
6 moderate; three, low; and four, insufficient.
7 Now beginning the vote.

8 (Voting)

9 MS. ALLEN: Perfect. Thank you.
10 Results are as follows: Thirteen high, four
11 moderate, no low, no insufficient.

12 DR. PACE: Okay. So now we'll
13 move onto validity. And I have a couple more
14 slides, Nadine, to talk about some notes on
15 validity.

16 MS. DORIAN: Yes, they're on there
17 now actually. It's in the in-person meeting
18 folder. There are PDFs in there.

19 DR. PACE: And we should just
20 mention that the notes that Jim was
21 referencing that staff put together, I know
22 Lauralei sent out notes last week, is in -- at

1 the beginning at the measures. It says "Staff
2 Review." There's an Excel file that has each
3 of them.

4 Okay. So just a couple notes on
5 validity. This is primarily about the degree
6 of confidence and the inferences or
7 conclusions that are made based on the basis
8 of the measure, either about the patients at
9 the patient-level scale or about the quality
10 of the health care units when you use the
11 computed performance score.

12 Again, this is not a fixed
13 property and generally is developed over time.
14 I think it's important to realize there are
15 many approaches to validity testing and often
16 with various names. So you'll see this, and
17 it seems like different disciplines use
18 different terminology, but it basically comes
19 down to testing some hypothesis about how the
20 measure performs. For example, how it relates
21 to other measures of the same construct, how
22 it's related or different from other

1 constructs, how it distinguishes groups of
2 patients that are known to differ on the
3 construct, or predicts performance on another
4 measure.

5 CO-CHAIR MERLINO: I think there's
6 been an question of race and language
7 inclusion. Maybe we could just have the
8 developer briefly comment on that?

9 MR. HASKINS: So, this is Matthew
10 Haskins again. Regarding the concerns related
11 to having it being an English version, when
12 you look at the distribution of populations on
13 the graphics in our test sample, those
14 populations on the graphics are very, very
15 similar to the population demographics that
16 are utilized in hospice across the nation at
17 this point in time. So while it is a
18 limitation of the survey to not have it tested
19 -- and we do have untested Spanish versions
20 and other language versions that are being
21 utilized, that -- well, on the tested version
22 that is in a different language, the English

1 language version is still capturing those --
2 not those values, but very specifically the
3 same patient demographics that you see
4 utilizing hospice across the country.

5 DR. TENO: Matthew, can I just add
6 a little bit of a correction to that?

7 MR. HASKINS: Sure.

8 DR. TENO: Because we did make a
9 Spanish version available that we did test.

10 (Simultaneous speaking)

11 DR. TENO: The issue is despite
12 making it available, no one really felt the
13 need to use it.

14 DR. SPENCE: Joan, we do have some
15 hospices that pick it up. We've given it out
16 on request. So far the feedback we've then
17 got back from it was that they felt again that
18 there was some particular wording that they
19 said, no, this is not what our particular
20 population -- one of our translators wants to
21 change.

22 So what we did was we allowed

1 those hospices that were using Joan's tested
2 version to make the changes they felt were
3 necessary. However, we asked them to keep the
4 questions in exactly the same order, not to
5 delete any. And then when they came to give
6 us their responses, which was done online,
7 that they then are able to parallel, go ahead
8 and choose the responses based on the English
9 version because the formatting was identical.

10 So within what we have here, we
11 have to rely on the demographic information to
12 tell us which people of Hispanic -- with that
13 ethnicity are responding to it. But we don't
14 have a designation as to whether they were
15 given a Spanish-language version or not.

16 But as Joan said, the bottom line
17 here is is that the uptake use on this has not
18 been huge and it has been relatively isolated.
19 There are single hospices that have a larger
20 enough Hispanic population that speak Spanish
21 or are more comfortable with Spanish and that
22 there is some utilization. But we did not get

1 enough response back that we were able to
2 analyze those separately even though we
3 requested that they identify and let us know
4 what they were doing.

5 CO-CHAIR PARTRIDGE: Sherri and
6 then Lisa. Sherri?

7 MEMBER LOEB: Just a quick
8 comment. I don't think the fact that it's not
9 available in Spanish or any language should be
10 a reason to not allow it to go forward,
11 because if there is a population that's not
12 English-speaking that can benefit by it, there
13 are language lines. There are ways to
14 eventually move it to another language. But
15 in the meantime, by not allowing it to move
16 forward you're hurting the larger population
17 that can use it now. So, I mean, in the
18 future we can move it forward and we can use
19 it to utilize in the population that doesn't
20 speak English by other means.

21 MEMBER MORRISE: So if I'm correct
22 in thinking we're looking at its validity to

1 the reported population, not necessarily the
2 validity to an expanded population that we
3 would like to see measured in the future.

4 DR. PACE: That's correct. I
5 think the question that comes up is is that
6 clear, and that may be something for
7 discussion in terms of if a hospice is taking
8 care of a primarily Spanish-speaking
9 population or non-English-speaking population,
10 are they just not going to be included, or how
11 do you interpret that? But I think you're
12 right, we need to focus on the survey as how
13 it's being used and the reliability and
14 validity that they presented.

15 One other thing about the validity
16 is that we also consider threats to validity
17 here in your overall vote, which means case
18 mix adjustment, exclusions, whether it can
19 differentiate, whether there are different
20 modes or different languages. So it's a lot
21 that goes into validity.

22 CO-CHAIR PARTRIDGE: Chris?

1 MEMBER STILLE: Yes, I just wanted
2 to quickly echo what Sherri said. I think
3 measure developers can get excited when things
4 get endorsed and that can actually spur them
5 on to testing it in other populations.

6 I had a question also. When NQF
7 endorses a measure are there sort of things
8 that go along with it saying we endorse this,
9 and by the way, it's probably only valid in
10 XYZ population?

11 DR. PACE: That's a good question.
12 We don't really explicitly state that, though
13 we are endorsing the measure as specified.
14 And I think part of the question is should
15 this be more explicit that it's English
16 language in terms of its primary use so that
17 people better understand that? And it's a
18 good question. It's probably something we
19 need to consider for these patient-reported
20 outcomes more carefully so that we can have
21 some explicit information about that.

22 CO-CHAIR PARTRIDGE: Becky?

1 MEMBER BRADLEY: Yes. Well, I do
2 think it's a good question and I think it
3 doesn't just apply to the patient-reported
4 outcomes, because we are seeing where NQF-
5 endorsed measures for one setting are being
6 applied to another setting. And so, I do
7 think that's something NQF -- and that's
8 probably a discussion for a different time,
9 but I do think that is very important, that
10 NQF consider the population that it is
11 applicable for and look at how those measures
12 are then expanded to other settings where
13 they've not been validated.

14 MEMBER MORRISE: Well, I just
15 wanted --

16 CO-CHAIR PARTRIDGE: Sherri, is
17 your card still up?

18 MEMBER MORRISE: Yes, I just
19 wanted to do a quick follow-up. So we're
20 voting on the validity to the population
21 specified, but the population isn't
22 necessarily specified in explaining this to

1 the public.

2 The second part of my point would
3 be that while providing this exact same survey
4 in a Spanish language version wasn't discussed
5 in the validity and reliability in terms of
6 looking at how that may vary from the overall
7 population wasn't explained -- that would have
8 been nice, but my suspicion is that a Spanish
9 language population has such significant
10 cultural differences in terms of death and
11 dying that a measure should be made
12 specifically to address their population and
13 cultural background.

14 CO-CHAIR PARTRIDGE: Len?

15 MEMBER PARISI: I had a blend of
16 what Lisa was saying. I think cultural norms
17 is such an important factor in hospice and end
18 of life care that it is important to recognize
19 that when an instrument is only in English, it
20 does only address that population. I mean,
21 there can be inferences, but cultural norms
22 are so important in end of life care.

1 And practically speaking, there
2 are two representatives here from large
3 hospices in New York City and English works
4 for us, but also we need Chinese, we need
5 Russian and we need Spanish. So I think you
6 can't have this discussion without
7 acknowledging the fact that it does not
8 reflect the entire population that we serve,
9 and this is an important issue for that
10 population as well.

11 I'm not saying that it's not
12 something we should be endorsing because it
13 doesn't reflect that, but I think it needs to
14 be acknowledged that it's an English-speaking
15 instrument.

16 MEMBER DOWDING: Sorry, can I just
17 add one more comment to that? I think it's
18 not just English-speaking. There's also
19 issues of culture within that. And the point
20 I was making is 93 percent of the respondents
21 identified themselves as white. So it's not
22 even that it's cultural in terms of language.

1 It's also culture in terms of other cultures
2 and ethnicities. So that was my concern, is
3 that it's valid for a certain type of
4 population.

5 CO-CHAIR PARTRIDGE: Carol?

6 DR. SPENCE: I'm sorry, was there
7 a question there? I heard that as a comment.
8 Could you repeat, please?

9 CO-CHAIR PARTRIDGE: No, this is
10 for one of our Committee Members, Carol.

11 MEMBER LEVINE: Yes, I just wanted
12 to say we at the United Hospital Fund have a
13 series of family caregiver guides including
14 one on hospice and palliative care, and
15 they're in four languages. And we have found
16 that the Spanish language version, which is a
17 generic Spanish language version -- it doesn't
18 take into account the people of Spanish origin
19 in California -- it's generic -- is as often
20 downloaded as the one that's in English. So
21 I think we can take this to an extreme of
22 every specific cultural nuance.

1 The main thing is does it work for
2 most of the people in that -- whose primary
3 language is something else? Because the
4 cultural norms may vary from one Hispanic
5 group to another Hispanic group, certainly.
6 And the Russian population definitely does
7 that. Chinese as well. So I think it's
8 important to recognize, but not to obsess
9 about it. And I think that it is mostly
10 important to acknowledge that the testing was
11 done mostly on English-speaking.

12 CO-CHAIR PARTRIDGE: I'm looking
13 at the clock and I think we all need a break.
14 So are we ready to vote, or do you think --
15 I'm looking to staff for judgment here. Can
16 we complete this do think in the next five to
17 seven?

18 (No audible response)

19 CO-CHAIR PARTRIDGE: Yes? Okay.

20 DR. PACE: So I think these are
21 good points that are brought up about the
22 validity. It's definitely population-

1 specific. And I think the question is in
2 terms of validating an instrument, it does
3 make a difference that you include the
4 populations that are going to be using it and
5 sometimes it requires -- if there are
6 consistent differences in how they respond to
7 items that may require some adjustment of the
8 score based on patients with certain language
9 or cultural differences.

10 So I think in terms of your voting
11 on validity, it should be based on the measure
12 as its specified. And for the target
13 population it may be that's something that
14 needs be more specific in the target
15 population, that it's for English-speaking
16 population, if that would address some of the
17 concerns. And I'll just ask those who raised
18 that whether that would be of interest.

19 (No audible response)

20 DR. PACE: So Lee's saying let's
21 go ahead and vote on it as its been specified
22 and then if there are issues, we can come back

1 to that. I think that's probably the best
2 approach. So on validity?

3 MS. ALLEN: So we're voting on
4 validity. One, high; two, moderate; three,
5 low; and four, insufficient. Starting the
6 vote now.

7 (Voting)

8 MS. ALLEN: And the results are
9 in. Seven high, nine moderate, one low and
10 zero insufficient.

11 DR. PACE: Okay. So why don't we
12 move on to feasibility and then usability? So
13 basically for the surveys, these are not going
14 to be in the EHR and generally require
15 additional effort to submit them, but we'll
16 ask the group that kind of looked at
17 feasibility or anyone who wants to make a
18 comment about feasibility for discussion, and
19 then we can vote.

20 CO-CHAIR PARTRIDGE: Debra?

21 MEMBER SALIBA: Can somebody tell
22 me what the response -- this is a mailed

1 survey -- what the response rates are? Do you
2 get that data back from the hospice agencies
3 that mailed them out?

4 CO-CHAIR PARTRIDGE: Carol, did
5 you hear that question?

6 DR. SPENCE: Yes. So our response
7 rate runs around 40 percent. It was a little
8 higher back a few years ago. And as Matt
9 said, we've had other -- we're curtailing of
10 new hospices join. And then we made some
11 changes to the survey a couple years ago and
12 we saw a dip in the response rate. And it's
13 come back up a bit. But it's around 40
14 percent, plus or minus, on any given quarter.

15 CO-CHAIR PARTRIDGE: So, Carol, is
16 that 40 percent of hospices or 40 percent of
17 people to whom hospice --

18 DR. SPENCE: It's the return
19 rate --

20 CO-CHAIR PARTRIDGE: Okay. Thank
21 you.

22 DR. SPENCE: -- on the mailed

1 surveys.

2 CO-CHAIR PARTRIDGE: Thank you.
3 Any further comments, questions?

4 (No audible response)

5 CO-CHAIR PARTRIDGE: Ready to vote
6 on feasibility?

7 MS. ALLEN: So we're ready to vote
8 on feasibility. One, high; two, moderate;
9 three, low; and four insufficient. Starting
10 the clock.

11 (Voting)

12 MS. ALLEN: Thank you. And the
13 results are in. Nine high, seven moderate,
14 one low and zero insufficient.

15 DR. PACE: Okay. Then we move on
16 to usability and use. And here we want to
17 know whether it's in use especially for an
18 accountability application based on what we
19 saw in the submission form that it's not used
20 for public reporting. It's in use, but my
21 understanding is that the public could not
22 look up a particular hospice to get their

1 score on this.

2 And, Carol Spence, that's correct?

3 DR. SPENCE: Yes, that is correct.

4 DR. PACE: Okay. Comments,
5 questions about --

6 MEMBER VAN ZYL: I have a question
7 for the developer. Is it possible for a
8 family to call the hospice and request that
9 information if they can't get it online?

10 DR. SPENCE: About a particular
11 hospice?

12 MEMBER VAN ZYL: Yes.

13 DR. SPENCE: Is that what you
14 mean? Well, I mean, some hospices put some of
15 their scores out in their information that
16 they have online, but that is up the hospices
17 to determine whether they want to put this out
18 or not.

19 The thing that NHPCO -- our
20 approach philosophy on public reporting has
21 been that public reporting of the survey
22 really needs to come from CMS. We cannot

1 enforce, because this is not -- CMS for the
2 CAHPS survey is requiring third party or
3 vendor survey administration. We cannot
4 require that. And so, a lot of hospices do
5 their own mailing. A lot of hospices do their
6 own submissions. And so we cannot enforce
7 with the same authority as CMS accountability.
8 So to have the playing field completely fair
9 we decided not to go the public reporting
10 route with this.

11 On the other hand, some of the
12 vendors that have chosen to do this did some
13 of their own ranking of hospices and gave that
14 out to the hospices to use for marketing, and
15 we did not approve of that. So this has been
16 a quality improvement measure. This is the
17 way we presented it. And again, CMS gave very
18 serious consideration to adopting this measure
19 when the quality reporting program was
20 developed and decided to go with Hospice
21 CAHPS. So we wanted to continue endorsement,
22 as I said earlier in the introduction, for

1 this measure up until the time that Hospice
2 CAHPS has gone through the endorsement process
3 and we wanted to make sure that hospices that
4 were using endorsed measure if they used FEHC.

5 CO-CHAIR PARTRIDGE: Thank you,
6 Carol.

7 Len?

8 MEMBER PARISI: This is for the
9 developer. I know that a lot of hospices
10 report their data to NHPCO. Do you provide
11 any benchmarking or reporting to the public
12 if --

13 (Simultaneous speaking)

14 DR. SPENCE: Absolutely. We have
15 very in-depth quarterly reports for them, and
16 then we also do a national-level report that's
17 an annual roll-up.

18 DR. PACE: Okay. So just a note
19 about usability and use; and actually I should
20 have said this about feasibility, it's not a
21 must-pass criterion. And so, in terms of
22 being used for public accountability and

1 improvement, you can vote it high, moderate or
2 low in terms of -- it's not going to
3 necessarily be a show stopper. And at the end
4 we'll have one vote on your final
5 recommendation. But I just wanted to let you
6 know that a low vote here does not mean that
7 it will not pass. Same way of feasibility.

8 CO-CHAIR PARTRIDGE: Ester, do I
9 see a card up?

10 MEMBER NEUWIRTH: So the
11 improvement on this measure since it was
12 developed is pretty insignificant it looks
13 like. I'm just wondering. So it looks like
14 there's an increase in the number of people
15 who are using the measure, but there's no sign
16 of improvement based on measuring. So I'm
17 curious just about the value of the use.

18 CO-CHAIR PARTRIDGE: I think that
19 goes back to Debra's question earlier where --
20 response of the developer -- and I'm sorry I'm
21 paraphrasing for you here, but I'm kind of
22 moving us along -- was that for those hospices

1 that had been using this for a while, they've
2 been able to stratify their data and the trend
3 is that they're improving. But the overall
4 average changes is being held a little lower
5 by the fact they have new ones coming in all
6 the time. I hope I'm saying that accurately.
7 Yes? Okay.

8 MR. HASKINS: That's pretty good,
9 yes.

10 CO-CHAIR PARTRIDGE: Are we ready
11 to vote?

12 (No audible response)

13 MS. ALLEN: We're starting the
14 vote on usability and use. One, high; two,
15 moderate; three, low; and four, insufficient
16 information.

17 (Voting)

18 MS. ALLEN: All votes are in.
19 Five high, seven moderate, five low and zero
20 insufficient information.

21 DR. PACE: Okay. So we'll move
22 onto the final vote, which is overall. Now

1 considering all of the criteria, do you
2 recommend this measure as meeting suitable for
3 endorsement? This is the Committee's
4 recommendation and what would be put out for
5 public comment.

6 MS. ALLEN: Overall suitability
7 for endorsement of Measure 0208, Family
8 Evaluation of Hospice Care. Starting to vote.
9 One, yes. Two, no.

10 (Voting)

11 MS. ALLEN: All votes are in.
12 Sixteen yes, one no.

13 DR. PACE: And I'll just mention,
14 because there was a note on that slide, that
15 this will be pending our final discussion
16 about competing and related measures. So this
17 means that the measure looked at --
18 individually you would recommend, but we will
19 have to come back to it because we have two
20 other measures in this space. So for now this
21 is something we'll come back to.

22 CO-CHAIR PARTRIDGE: And now

1 playing dragon lady, we're going to shorten
2 our break, if you all will forgive us, to
3 11:30. Then I assume we'll also delay lunch
4 a little bit. We've got two measures in the
5 next bucket. I think some of what we already
6 talked about will come up again in connection
7 with the care measure and probably we'll move
8 along a little more rapidly as a result.

9 And I know the developers for
10 those two measures are standing by, so I don't
11 want them sitting out on the phone too much
12 longer.

13 DR. TENO: Actually, this is Joan
14 Teno, I have a really hard stop at five after
15 12:00 that I can't get out of because I've
16 been out of town and I have --

17 CO-CHAIR PARTRIDGE: Well, that
18 gives us 30 minutes to consider it, Joan, so
19 we will do our best.

20 DR. TENO: All right. I'm booked
21 literally all day.

22 CO-CHAIR PARTRIDGE: That's fine.

1 DR. TENO: Thank you.

2 (Whereupon, the above-entitled
3 matter went off the record at 11:21 a.m. and
4 resumed at 11:30 a.m.)

5 CO-CHAIR PARTRIDGE: We're going
6 to move on to Measure No. 1632, Consumer
7 Assessments and Reports of End of Life.

8 Katherine and Lisa and Debra, if
9 we could have everybody sitting down, please?

10 Okay. We're going to start on
11 1632, the CARE, Consumer Assessments and
12 Reports of End of Life. And we'll start with
13 Joan Teno. If you'd give a couple-minute
14 introduction to 1632?

15 DR. TENO: Sure. And I'm going to
16 be very brief. So I was requested by Sean
17 Morrison and a group of people to submit this
18 measure to fill a void for having some type of
19 measurement to look at a systems perspective
20 on end of life care. So they wanted a measure
21 that would allow you to examine the quality of
22 end of life care irregardless of the setting

1 of care. So they wanted a measure that could
2 go across settings.

3 This measure is largely been based
4 on the research they have done using a
5 mortality fall-back survey to study bereaved
6 family members' perceptions of the quality of
7 care based on the site of care and focusing on
8 the last place of care in the last week of
9 life.

10 I've been in discussions with NQF
11 staff because I do have concerns in that in
12 the past three years my focus has been on
13 creating a new version of a FEHC and working
14 with the rating team on development of the
15 Hospice CAHPS survey that we are only now
16 starting to engage with a large ACO, a large
17 corporation that has 22 ACOs to now chart time
18 to get this measure to be used in the ACO
19 context. So I think there's a concern in that
20 we haven't done the reliability testing at the
21 unit that you would want.

22 DR. PACE: So, and let me just

1 mention to the Committee, as Joan mentioned,
2 we had some conversations with them about
3 that. And as I've told you and we've talked
4 about several times, the new guidance is to
5 have testing at both levels. But because this
6 is the first time we're applying those new
7 criteria, we asked Joan to let the Committee
8 evaluate the measure and then we can see where
9 we are after you discuss the criteria whether
10 it will stay in the mix or whether they will
11 withdraw at this point given that they're
12 working on another project. But we wanted to
13 really provide the opportunity for the
14 Committee to weigh in on applying those new
15 criteria and whether you had any concerns
16 about it.

17 CO-CHAIR MERLINO: So any members
18 of the Committee that reviewed this have any
19 general comments about the measure?

20 (No audible response)

21 CO-CHAIR MERLINO: The developer?

22 DR. PACE: No, that's okay. Why

1 don't we go ahead and move onto the evidence,
2 which is again the same question: Are there
3 health care structures, processes and outcomes
4 that influence this experience? And there I
5 guess was a little mix-up with the submission
6 and there's a -- Joan sent a separate table;
7 Nadine, if you could bring that up, where they
8 did a crosswalk of preferred hospice practices
9 that related to this measure. But we'll bring
10 that up. And it's also available for the
11 Committee on SharePoint, but just wanted to
12 show you this. And we'll ask, like Jim said,
13 the group that reviewed this: Carol, Brian,
14 Sherri, Jim, Carin in terms of health care
15 practices that influence this, if there's
16 anything you want to say.

17 CO-CHAIR MERLINO: Peter?

18 MEMBER THOMAS: I saw this phrase
19 a number of times throughout the different
20 measures we looked at, that the Committee will
21 need to substitute its judgment that at least
22 one health care structure process,

1 intervention or service influence the
2 experience of preparation for self-care.

3 So I just wondered; I know that
4 each measure needs to relate to that somehow,
5 why aren't the requesters making that clear
6 and what does that exactly mean for us?

7 DR. PACE: Right. So in this case
8 they did end up submitting this, so they do
9 have what they considered as appropriate. And
10 so, that was an initial comment, but they did
11 submit the additional information. But what
12 it means, the reason we put that in there is
13 when they hadn't, I guess the thinking is that
14 this Committee could make a judgment on that
15 for these PRO measures, whether it is
16 something that the health care unit can
17 affect.

18 In terms of why the developers
19 didn't submit it, I think perhaps they didn't
20 understand the question. And we had had
21 several conference calls and tried to provide
22 some guidance in advance, but in some cases

1 there was probably a misunderstanding of what
2 we were asking for.

3 CO-CHAIR MERLINO: Sherri?

4 MEMBER LOEB: In reading this and
5 from the group call that we had it seemed --
6 and they had even said so, that this was more
7 of a QI project rather than outcomes or a --
8 that we were going to be voting on. So that
9 was my question. And I don't know if that
10 comes here.

11 DR. PACE: Probably not here, but
12 it is certainly a consideration when we get
13 into usability.

14 MEMBER LOEB: Okay.

15 DR. PACE: And that actually is
16 going to come up in the reliability --

17 CO-CHAIR MERLINO: Estee, do you
18 have a comment? Your card is up.

19 MEMBER NEUWIRTH: (No audible
20 response)

21 CO-CHAIR MERLINO: No? Lee, do
22 you have something?

1 CO-CHAIR PARTRIDGE: Sherri
2 actually raised my first issue, and it's not
3 -- we'll get there.

4 CO-CHAIR MERLINO: Any other
5 comments about evidence? Deb? Sorry.

6 MEMBER SALIBA: I think this table
7 does a really good job of tying together sort
8 of the rationale behind the structure-process-
9 outcome links for each one of these. So
10 thanks to the developers for sending it.

11 CO-CHAIR MERLINO: Great. Any
12 other comments, evidence?

13 (No audible response)

14 CO-CHAIR MERLINO: All right.
15 Let's vote.

16 MS. ALLEN: So we're going to
17 start the voting on Measure 1632, CARE, and
18 we're starting with evidence. One, yes. Two,
19 no.

20 MS. DORIAN: And, Liz, you can
21 send your vote via chat.

22 MS. ALLEN: Starting the clock.

1 (Voting)

2 MEMBER MORT: I just sent it.

3 MS. DORIAN: Great. Thanks. Got
4 it.

5 MS. ALLEN: Please vote again.

6 We're still missing --

7 (Voting)

8 CO-CHAIR MERLINO: Seventeen plus
9 this one, right?

10 MS. ALLEN: Okay. Please vote
11 again. Sorry. Please point in my direction.

12 (Voting)

13 MS. ALLEN: Okay. Eighteen yeses.

14 DR. PACE: Okay. So we'll move on
15 to performance gap. Nadine, you want to bring
16 up this -- okay.

17 CO-CHAIR MERLINO: Debra?

18 MEMBER SALIBA: So for performance
19 gap I think there's clearly a performance gap
20 in this area, particularly because we're not
21 looking just at hospice agencies, but we're
22 looking across different care settings. And

1 there is some information in here also about
2 -- I don't know -- I'm a little confused about
3 the divisions where it comes up about the
4 cultural and ethnic gaps in performance. Does
5 that come up here, or someplace else?

6 DR. PACE: Yes.

7 MEMBER SALIBA: Okay. So there's
8 also some evidence of differences by ethnicity
9 in terms of performance on this measure. And
10 I think that's a really important point to
11 bring out.

12 CO-CHAIR MERLINO: Any other
13 comments, performance gap?

14 (No audible response)

15 CO-CHAIR MERLINO: Very similar to
16 issues raised in the last instrument.
17 Any other points?

18 (No audible response)

19 CO-CHAIR MERLINO: We ready to
20 vote?

21 MS. ALLEN: Okay. We're starting
22 the vote for performance gap. One, high; two,

1 moderate; three, low; and four, insufficient.

2 Starting the clock now.

3 (Voting)

4 MS. ALLEN: The results are in.
5 Fourteen high, four moderate, zero low and
6 zero insufficient.

7 DR. PACE: Okay. So priority.
8 This addresses whether it's a high-impact
9 aspect of health care, affects large numbers,
10 consequences of poor quality, and also in 1C5,
11 this is specifically for PRO-PMs, how patients
12 or families were involved in identifying that
13 this is something of value and meaningful to
14 them.

15 CO-CHAIR MERLINO: So this issue
16 was specifically raised on the call. I don't
17 remember who did question it. Does anybody
18 want to talk about it or have any questions
19 about it? Any comments?

20 DR. PACE: And the submission form
21 I think said they conducted extensive focus
22 group testing, but no specific information.

1 But again, that's the area we'll talk more
2 about later. But does anyone want to make any
3 comments or move on to vote?

4 CO-CHAIR MERLINO: Questions?

5 (No audible response)

6 CO-CHAIR MERLINO: Okay. We'll
7 vote.

8 DR. PACE: So the question is --

9 (Simultaneous speaking)

10 DR. TENO: Can I just say that
11 there is a published paper that reports all
12 our focus group testing, and if you want me to
13 summarize that, I can summarize it. I
14 probably just didn't do it because it was just
15 a very bad spring for me.

16 CO-CHAIR MERLINO: Does anybody
17 need that? I think we're okay.

18 Debra, were you going to make a
19 comment?

20 MEMBER SALIBA: I was just going
21 to say, so we're talking about whether this is
22 a high priority area and I was going to point

1 to the paper that was in here, so that's fine.

2 CO-CHAIR MERLINO: Okay. Any
3 other thoughts?

4 (No audible response)

5 CO-CHAIR MERLINO: Then we can
6 vote.

7 MS. ALLEN: So now we're voting on
8 high priority. One, high; two, moderate;
9 three, low; and four, insufficient. Starting
10 the vote now.

11 (Voting)

12 MS. ALLEN: All votes are in.
13 Sixteen high, two moderate, zero low, zero
14 insufficient.

15 DR. PACE: Okay. So we'll move on
16 to reliability, and this includes precise
17 specifications, so if there is anything
18 unclear about the specifications to
19 specifically note that. One of the things
20 that we asked that didn't get with the initial
21 submission was the actual survey, so that is
22 in your materials on SharePoint. And then of

1 course reliability testing which was done at
2 the patient level instrument. And as Joan
3 mentioned, they haven't had time to address
4 performance measure testing because of not
5 having that data from implementation.

6 So again, this is one measure.
7 It's an overall composite as specified. And
8 based on our current guidance about having
9 testing at both levels, we would essentially
10 say that this would be insufficient
11 information, but we'd like to have some
12 discussion with all of you in terms of whether
13 you have any concerns about our current
14 guidance.

15 As we mentioned, we're intending
16 to endorse performance measures that are used
17 in accountability applications, and that was
18 the thinking behind the PRO project group in
19 terms of why these should have testing at the
20 computed performance score level. So I'll
21 just stop and see what questions or comments
22 people have.

1 CO-CHAIR MERLINO: Dawn?

2 MEMBER DOWDING: Can I just ask
3 the developer for clarification? Is it right
4 that the data on reliability and validity was
5 actually collected in 2001 and '2 and it
6 hasn't been updated since then?

7 DR. TENO: Yes, that's true.

8 CO-CHAIR MERLINO: Anybody else?

9 (No audible response)

10 CO-CHAIR MERLINO: Karen, can you
11 go over just why the group, the staff
12 recommended that it was insufficient to meet
13 the reliability algorithm?

14 DR. PACE: Right, so the algorithm
15 doesn't specifically address the PRO-PMs in
16 terms of the fact that we're requiring testing
17 at both levels. So it's a good point that the
18 algorithm would say testing at one level would
19 be moderate and testing at -- testing at the
20 patient data level would be moderate and
21 testing at the performance score would be
22 high.

1 So the distinction is that the
2 guidance for the PRO-PMs is that they must be
3 tested at both levels. And the reason I'm
4 suggesting that would be insufficient is we
5 just don't know. We don't have the data to
6 know whether it's reliable at the performance
7 score level. We only have data at the patient
8 level. So this something we'll work through
9 together.

10 So the options would be to rate it
11 insufficient because it doesn't have testing
12 at that level, or to rate it moderate and we
13 can note that that was only at the patient
14 level and come back to that. I don't know if
15 anyone has any other options that they want to
16 bring up.

17 MEMBER BIERNER: So I just have a
18 comment that the nature of this survey or this
19 instrument is a variety of settings in which
20 the patient lived at the last days of live, so
21 it would be hard to know at what level you
22 would test this at an institutional or agency

1 level. It seems like it wouldn't be clear to
2 me which group you would go to for that
3 because it's not just -- it could be in the
4 home or in a variety of settings.

5 DR. PACE: And, Joan, can you
6 remind us what level this was specified for
7 for level of analysis? Is it any organization
8 or was it specifically ACOs?

9 DR. TENO: So, the thinking was as
10 we're moving to capitated payments that you
11 needed to be able to test across setting of
12 care. So ideally as we move forward with
13 this, this would be an instrument that an NMA
14 plan could use if they want to look at how
15 they're caring for dying patients. And it
16 also could be an instrument that an ACO could
17 use. But I'm very honest with you that we're
18 not totally there yet.

19 CO-CHAIR MERLINO: Any other
20 comments?

21 DR. BURSTIN: In some ways because
22 the guidance is so new we also -- we're a

1 little hesitant to push that it has to be met
2 since it's literally the first time out of the
3 box. So we want to at least present that
4 information to the Committee saying the PRO
5 Committee had just come up with this guidance
6 fairly recently. This would be the very first
7 time we have implemented it, so if the
8 Committee wished us to allow them to move
9 forward with a moderate, understanding
10 additional work might be done in the future,
11 that's something that could be done as well.

12 CO-CHAIR MERLINO: Peter?

13 MEMBER THOMAS: Is there anything
14 the developer would like to say to address
15 this potential concern about an insufficient
16 rating on this item?

17 DR. TENO: The only thing I can do
18 is be very honest with you where we are. We
19 only have testing at the individual level. I
20 think we have sufficient evidence at the
21 individual level. In the future we need to
22 address this concern. Can I give you any

1 evidence beyond what I have right now? No.

2 CO-CHAIR PARTRIDGE: This is Lee.
3 I wanted to ask Karen and Helen a question
4 here. This measure is similar to the one we
5 discussed earlier this morning, and we know
6 down the road not too far we're going to be
7 getting a CAHPS Hospice survey. Would it be
8 likely when we review the CAHPS Hospice survey
9 later on that this measure also would come
10 back for consideration at that same time?

11 So if we said go ahead and do a
12 little more work on this and let it go
13 through, it's almost like doing a time-limited
14 endorsement, but I didn't use that phrase.

15 DR. TENO: Can I address that a
16 little bit, because any further work on this
17 measure will be done within the context of
18 working with the exact same team, and I was a
19 member of the team, who created the CAHPS
20 Hospice instrument. So from the onset I
21 understand the importance of harmonization.
22 You should realize the CAHPS Hospice tool,

1 which we're not discussing, but -- really
2 deals with hospice. That this instrument
3 must deal with multiple settings of care, so
4 it's going to have additional content.

5 CO-CHAIR PARTRIDGE: Yes, Joan, I
6 think we appreciate that. It's just a
7 question of whether they, the NQF will group
8 them together so that we can in essence take
9 a second look at this measure at that time as
10 well.

11 DR. TENO: Yes, and believe me --
12 I think what I tried to do and slapped in an
13 email message to NQF staff is, you know, I'm
14 not invested in keeping this measure per se,
15 but I'm invested in moving fields forwards.
16 So once we have a better tool, my strategy in
17 life is to try to make that a better tool,
18 that harmonizes, available.

19 DR. PACE: But, Joan, correct me
20 if I'm wrong, didn't you also say that you
21 were working on a CAHPS version of this CARE,
22 the --

1 DR. TENO: The exact plan is now
2 to -- now that, at least in my hopefulness,
3 that we are done with CAHPS Hospice, it's now
4 to merge this work that I've done on this
5 instrument with the CAHPS Hospice instrument
6 to create a new instrument. And that's why I
7 wasn't afraid to withdraw this instrument. I
8 know that we need to -- now that we're far
9 along with CAHPS Hospice, I need to now go
10 back and take the work that I've done in this
11 instrument and bring it up to the wonderful
12 work that my colleagues at CAHPS, that are
13 working on the CAHPS Hospice team, has done to
14 harmonize it.

15 DR. PACE: So I think the question
16 for the Committee then is -- and as you
17 mentioned, Joan has been fully aware of kind
18 of the new guidance on criteria, and one
19 approach is for them to withdraw this measure
20 and then bring the CAHPS cross-setting
21 bereaved family measure in when it's ready.
22 And it really depends on whether this

1 Committee agrees with applying the criteria
2 and the guidance that for NQF endorsement the
3 measure should have testing at both levels, or
4 whether there's any concern about that.

5 CO-CHAIR MERLINO: Any other
6 thoughts? I think we have to probably use the
7 criteria.

8 (No audible response,)

9 CO-CHAIR MERLINO: No?

10 DR. PACE: So why don't we vote on
11 reliability, and that will kind of solidify
12 where you're at with it. If you agree with
13 the testing at both levels, it would be
14 insufficient. And if that's the case, then
15 we'll stop there and we'll be talking with
16 Joan about the next steps with their new
17 measure.

18 CO-CHAIR MERLINO: Yes, our
19 sidebar conversation was just that, the
20 criteria holds the measures to a higher
21 standard and provides the guidance for all of
22 us. Do you have a comment?

1 MEMBER PARISI: I just have a
2 question. Was it established that at the
3 level of delivery that it's been tested, or
4 just at the individual level? So for example,
5 a nursing home versus an inpatient hospice
6 unit, or a hospital for end of life care. I
7 didn't hear that.

8 DR. TENO: It was tested at the
9 individual patient level and then within each
10 setting category, although I didn't present
11 the data there.

12 DR. PACE: But each setting
13 category it was lumped at the patients, not
14 individual nursing homes or -- is that --

15 DR. TENO: No. No, right. Right.
16 Only at the patient level in each.

17 CO-CHAIR MERLINO: Okay. Why
18 don't we move forward with the vote?

19 MS. ALLEN: So we're voting on
20 reliability, and it's including the
21 specification and testing. One, high; two,
22 moderate; three, low; and four, insufficient.

1 Starting the clock now.

2 All votes are in. Zero high, six
3 moderate, two low, and ten insufficient.

4 DR. PACE: Okay. No. No, it's
5 not. It's more than 60 percent in the low and
6 insufficient. Yes. Right. So we would stop
7 here then. And, Joan, we'll continue
8 conversations with you offline on next steps
9 and definitely everyone is interested in
10 having the new instrument and the performance
11 measures with the new instrument.

12 DR. TENO: Yes.

13 DR. PACE: And I thank you for
14 bearing with us. I know we had this
15 conversation, but we definitely wanted to have
16 more Committee discussion about it as well.
17 So appreciate it.

18 DR. TENO: Sure. Yes, and my only
19 urgency is just that I've been traveling and
20 I have meetings from -- my day is not going to
21 end until very long. So thanks a lot. I'll
22 sign off. Thank you very much.

1 DR. PACE: Thank you.

2 CO-CHAIR MERLINO: Okay. Moving
3 to 1623?

4 MS. DORIAN: So we're moving to
5 Measure No. 1623 now, which is the bereaved
6 family survey from the PROMISE Center. So do
7 we have Mary Ersek or Hien Lu on the call to
8 introduce the measure?

9 DR. ERSEK: Yes, we have Mary
10 Ersek, Hien Lu and Dawn Gilbert. I'll
11 introduce it. The bereaved family survey
12 arose out of a research study that was funded
13 by the VA to Dave Casarett, who actually also
14 is probably familiar to all of you because
15 he's also been involved with the FEHC and also
16 worked with Joan.

17 But anyway, this was developed.
18 The validity testing has been published, and
19 we can talk about that further. And then in
20 2008, the VA made a huge investment of
21 resources into the Comprehensive End of Life
22 Care Initiative. And the bereaved family

1 survey at that point -- and it used to be
2 called FATE, by the way, so Family Assessment
3 of Treatment at End of Life -- but then it
4 morphed into what -- when it became a quality
5 improvement and a performance measure, it was
6 the bereaved family survey. So the PROMISE
7 Center was set up to administer the survey,
8 collect the data and report out.

9 We've evolved over time, but --
10 and the goal of the PROMISE survey -- so I
11 just want to put this in framework. Although
12 it's a performance measure, it was always
13 imbedded in a QI program. Our mission at the
14 PROMISE Center -- and we oversee kind of
15 everything BFS, is to reduce variability in
16 the quality of end of life care, because our
17 veterans are not likely to pick and choose
18 what VA hospital they're going to go to. Our
19 job is to ensure that they can get good care
20 at every VA facility.

21 We also have a mission to identify
22 and disseminate best practices, and that's why

1 we have always been integrally involved in
2 identifying those quality of care indicators
3 that are associated with higher bereaved
4 family scores.

5 I think there's a little bit of
6 confusion from the earlier phone call as to,
7 okay, what in fact is our performance measure?
8 And remember that just like the FEHC in other
9 measures, the bereaved family survey was
10 endorsed by NQF as a palliative care measure,
11 and when it was, and at the time, it was a
12 composite score. At some point in its
13 evolution at the VA there was a discussion
14 with the National Performance Measure Work
15 Group who suggested that we go with the
16 overall item, okay, alone, which is item No.
17 18.

18 And we did this for a couple of
19 reasons. Number one, it was easier to
20 interpret. In addition to the performance
21 measure, we also report out the scores on the
22 individual items. So our measure is like the

1 FEHC. We have a number of Likert scale items
2 that identify more specific elements of end of
3 life care. So we did that for
4 interpretability.

5 We did it for consistency, because
6 if we were to change any of the items --
7 because this is a living breathing tool. If
8 it was a composite score, then we would be
9 hard-pressed to compare -- let's say we added
10 an item on burial benefits, which veterans are
11 eligible for, and we didn't have that before,
12 we would have a hard time looking at trends
13 over time.

14 The third reason for doing it is
15 because our overall items are very similar;
16 admittedly not identical, to the overall item
17 on the compare -- or on the care, rather, on
18 Joan's instrument, as well as the FEHC. And
19 we felt as though -- or it was felt by VA
20 leadership that this was a good thing, that
21 while it wasn't actually apples to apples, it
22 was like McIntosh apples, to delicious apples,

1 as opposed to apples and oranges. I'll stop
2 there. Any other questions about this
3 instrument?

4 CO-CHAIR MERLINO: No, that's
5 good. Any comments about evidence?

6 DR. PACE: So the measure is just
7 the overall rating out of the whole survey,
8 and at least the performance measure that
9 they're submitting for NQF endorsement. And
10 so, they did submit some additional
11 information about structures and processes
12 that influence the overall experience. So any
13 comments about --

14 CO-CHAIR MERLINO: Questions?

15 CO-CHAIR MERLINO: All right.

16 Shall we vote on evidence?

17 DR. PACE: So the question is is
18 there health care structure, process,
19 intervention or service that will influence
20 the overall experience with care? Nadine?

21 MS. ALLEN: So now we're voting on
22 evidence. One, yes. Two, no. Starting the

1 vote now.

2 MEMBER SALIBA: While we're
3 voting, just sort of a point that I'd like to
4 ask. Is there any way to change the title so
5 that it indicates that this is VA? I think
6 that this is going to generate confusion, that
7 there are so many different measures out
8 there, and if there's some way to help
9 distinguish it, it might just help people.

10 DR. PACE: Yes, I think that's a
11 good point. We actually have asked and
12 suggested that these measure titles actually
13 indicate that it's a measure and not a survey.
14 And of course now this is the overall rating.
15 So there might be some ways for all of the
16 measures that we're looking at to be specific
17 about that, but I think we can deal with that
18 with the developer.

19 MS. ALLEN: The results are in for
20 the bereaved family survey 1623. And it's 18
21 yes, and zero no.

22 DR. PACE: Okay. We'll go on to

1 performance gap.

2 CO-CHAIR MERLINO: Questions,
3 comments about performance gap? There was
4 additional information submitted, as well, for
5 this criteria.

6 DR. ERSEK: I just wanted to, if I
7 may, point out there was a question on the
8 earlier measure. What has scores done? And
9 I mean, part of it is we're just lucky in the
10 VA to be tied into this huge network of data,
11 but if we you look at our scores, the scores
12 have consistently gone up, not by much, but
13 again when you're looking at these kind of
14 measures, HCAHPS or any kind of really global
15 measure, even a nudge of one or two percent,
16 we believe is significant.

17 The other kind of cool thing here
18 is, although we certainly don't have a
19 randomized control trial, we can link this in
20 our national databases with -- as these scores
21 have inched up, and these are national
22 facility scores, as these scores have inched

1 up, we can also demonstrate across the board
2 that we are providing more care in hospice and
3 palliative care units, which we would expect
4 to be better care. And this is throughout the
5 VA, but we also look at facility level. We
6 have increased the number of veterans who
7 receive a palliative care consult in the last
8 90 days of life, etcetera.

9 CO-CHAIR MERLINO: I think this
10 came up in the call as well, but it seems like
11 there's enough evidence for the performance
12 gap. Any questions or comments about it?

13 CO-CHAIR MERLINO: Is everybody
14 okay with moving on? Len? Sorry.

15 MEMBER PARISI: Unrelated
16 question. When we think about these measures
17 and voting on them, by definition an NQF
18 endorsed measure -- shouldn't we be thinking
19 nationwide, rather than just one particular
20 health system, as in this case?

21 CO-CHAIR MERLINO: That's a great
22 question.

1 DR. PACE: You know, you should be
2 thinking that it's a national standard, but
3 there's VA facilities all across the nation.
4 And I think the developer also submitted some
5 information about there's more diversity in
6 their population -- although albeit mostly
7 male, that there is some diversity. So
8 sometimes we've endorsed measures that are
9 being used in public reporting in one state.
10 So the key thing is that it could be used as
11 a national standard, albeit right now it's
12 being used particularly in the VA facilities.

13 But, Helen, I don't know if you
14 want to add anything?

15 CO-CHAIR PARTRIDGE: But I can
16 tell you that, as a matter of desire, it would
17 be nice eventually to have one measure.

18 DR. PACE: And that will be a
19 discussion when you -- for all the measures
20 you recommend, if they're kind of in the same
21 space, to have a discussion about whether we
22 need multiple measures.

1 MEMBER LEVINE: There are specific
2 questions that specifically relate to a
3 veteran's experiences that might not be
4 comparable in other populations. So I think
5 that's valuable to be able to relate to how at
6 the end of life veterans bring back their
7 combat experience, or whatever it is. It's
8 not similar.

9 CO-CHAIR MERLINO: Sure.

10 MEMBER LEVINE: So I think there's
11 value in keeping that part.

12 CO-CHAIR MERLINO: Any other
13 comments? Questions? Becky?

14 MEMBER BRADLEY: Just a question
15 for my own education. Did the VA hospitals
16 participate in the CAHPS programs? Are they
17 required to publicly report it?

18 DR. ERSEK: Yes.

19 MEMBER BRADLEY: So if there is a
20 CAHPS survey, they would be migrated to that
21 as well?

22 DR. ERSEK: I don't represent

1 that, but we do use the CAHPS. And I believe
2 there is a movement underfoot to put all VA
3 hospitals on the national reporting.

4 MEMBER SALIBA: It's not required.

5 DR. ERSEK: But I would have to --

6 CO-CHAIR MERLINO: Yes, I don't
7 think it's publicly reported.

8 MEMBER SALIBA: It's not required,
9 but the VA, as the developer alluded to
10 earlier, is trying to use measures that could
11 be compared to non-VA facilities, and to use
12 the nationally endorsed measures whenever
13 possible. But it's not a requirement, so we
14 can't assume that they would use it at this
15 point.

16 CO-CHAIR MERLINO: Okay. Why
17 don't we vote on performance gap?

18 MS. ALLEN: So we're voting on
19 performance gap, data demonstrated
20 considerable variation or overall less than
21 optimal performance across providers and-or
22 population groups. One, high; two, moderate;

1 three, low; and four, insufficient. Starting
2 the votes now.

3 All votes are in. Ten high, eight
4 moderate, zero low, and zero insufficient.

5 CO-CHAIR MERLINO: Okay. Moving
6 on to high priority. Comments?

7 CO-CHAIR MERLINO: Anybody want to
8 discuss it from the call?

9 DR. PACE: So they did indicate
10 that they did qualitative interviews with
11 family respondents in four VA facilities, so
12 they involved the family members. Any
13 additional comments?

14 CO-CHAIR MERLINO: Becky, are you
15 -- oh, that's okay. Any questions?

16 DR. ERSEK: If I can just say, I
17 mean, if you look, we responded to that
18 specifically. We developed it very similarly.
19 I'm afraid none of us is very creative. We
20 also, of course, referred to the consensus
21 guidelines, etcetera, in the development,
22 which I think we have in our original

1 application.

2 CO-CHAIR MERLINO: Okay. Shall we
3 vote on high priority?

4 MS. ALLEN: We're voting on high
5 priority. One, high; two, moderate; three,
6 low; and four, insufficient. And it addresses
7 a specific national health goal, or priority,
8 or data demonstrated a high impact aspect of
9 health care for PRO target population values
10 and finds meaningful. Starting the votes now.

11 All votes are in. Sixteen high,
12 two moderate, zero low, zero insufficient.

13 CO-CHAIR MERLINO: Okay. Now
14 we're going move on to reliability testing.

15 DR. PACE: This will also include
16 if there are any questions about the
17 specifications, if that's unclear.

18 DR. ERSEK: Do you want us to
19 respond to the information we got on Friday
20 afternoon about --

21 DR. PACE: About the tests? Maybe
22 -- yes, why don't we wait and let the

1 Committee speak and then --

2 DR. ERSEK: Okay.

3 DR. PACE: Well, let me just ask
4 you: we still did not have any testing at the
5 performance score level, so the question is do
6 you have that?

7 DR. ERSEK: I thought that's what
8 we submitted.

9 DR. PACE: Okay. Well, then let's
10 wait until we have the Committee talk, and
11 then we can come back to you. Thanks.

12 DR. ERSEK: Okay.

13 MEMBER BEVANS: My question for
14 the instrument developer is the denominator
15 statement. I'm wondering if you could justify
16 some of these exclusions, because it really
17 does reduce the overall number of people who
18 are eligible to be included in a performance
19 measure, in particular death by suicide, or
20 accidents, or deaths that occur in the
21 emergency department, or any of the others.

22 DR. ERSEK: Yes, the key point

1 there -- and actually I'll be honest with you,
2 it's not so much the suicide. The key thing
3 is we're asking families to tell us -- to
4 evaluate the quality of care that the veteran
5 received in the last 31 days of life.

6 So while we don't require that
7 someone's been in the hospital for 31 days,
8 and certainly the system has cared for this
9 veteran, we felt as though someone coming in
10 who spent less than 24 hours in a VA facility
11 in the last 31 days of life -- how much of
12 that could be influenced, or would there be
13 enough care for that veteran's family to judge
14 the care in the last 31 days of life?

15 MEMBER BEVANS: What if they're an
16 outpatient --

17 (Simultaneous speaking.)

18 DR. ERSEK: If their contact with
19 the VA was two hours in the emergency room.

20 MEMBER BEVANS: Any consideration
21 to simply asking have they received care in
22 the past 30 days? I'm concerned of course

1 that --

2 DR. ERSEK: Yes.

3 MEMBER BEVANS: -- by removing
4 some of these populations that, for example,
5 we may be limiting -- for example, the suicide
6 limitation, that we may lose some important
7 feedback about veterans who are challenged
8 with some mental health challenges, as an
9 example.

10 DR. ERSEK: Yes. And, well, many
11 of these -- well, anyway, we do know there are
12 psychiatric burdens, because we have those
13 data available to us. You know, I think it's
14 a good question, and actually we've just
15 switched to a mail survey. I think it's a
16 good question to raise. They are relatively
17 -- they represent -- in the whole scheme of
18 things, remember we have the -- well, our
19 population, we essentially sample our
20 population with those few exceptions, so we
21 have data on about 82,000 veterans and we have
22 bereaved family survey data on close to 36,000

1 of them. So I think they're relatively small
2 numbers. Nonetheless, we can look at these.

3 The other thing that we're able to
4 do, because again we have this administrative
5 and clinical data available to us, we're able
6 to compare those veterans, let's say, who
7 committed suicide. We can actually -- we
8 start with who died in the VA facility. And
9 we could do analyses on those. And I think
10 your point is well taken. And if there is a
11 significant difference -- I think what really
12 -- what it's stumbled is we're trying to
13 identify actionable strategies, and if
14 somebody's in the ER for two hours, do we
15 fault the -- or how can we improve that care?
16 ,Like can we get a palliative care consult in?
17 Is that appropriate?

18 CO-CHAIR MERLINO: Okay. I don't
19 want to cut you off, but I think we have --
20 Deb, did you want to --

21 DR. ERSEK: Okay.

22 CO-CHAIR MERLINO: You were going

1 to make a comment?

2 MEMBER SALIBA: I was just going
3 to ask also if they were in -- I think I was
4 leading into what you were about to say. If
5 they were in hospice, outpatient hospice,
6 would they be excluded of deaths within 24
7 hours admission without a prior
8 hospitalization of at least 24 hours in the
9 last 31 days of life? So if they were in
10 outpatient hospice, and then ended up in the
11 hospital for their last 24 hours, they would
12 be excluded from this sample?

13 DR. ERSEK: Yes.

14 MEMBER SALIBA: Okay.

15 DR. ERSEK: Because we don't do --
16 now, if you're talking about community
17 hospice, yes, because we don't -- we pay for
18 community-based hospice. We don't --

19 (Simultaneous speaking.)

20 MEMBER SALIBA: Right, at our VA
21 facility we do both community-based hospice
22 and we also -- our palliative care team

1 follows people in the outpatient setting. So
2 if those people hadn't been in the hospital in
3 the last 31 days of life, then they would be
4 excluded from this sample?

5 DR. ERSEK: Yes, I mean that said,
6 we are actually -- up until now this
7 instrument has always been used inpatient. Of
8 course most vets don't die inpatient, and so
9 we are extending the bereaved family survey to
10 other programs. We have to do it slowly
11 because of workload issues. For example,
12 we're moving out into our home-based primary
13 care programs. So right now they're excluded.

14 CO-CHAIR MERLINO: Karen --

15 DR. ERSEK: But in the future
16 we're actually going to include them.

17 CO-CHAIR MERLINO: -- can you talk
18 about the survey?

19 DR. PACE: Right. So, Jim is
20 asking about the testing. So, basically, what
21 we identified in the submission form is that
22 you reported a range of Cronbach's alpha --

1 DR. ERSEK: Yes.

2 DR. PACE: -- but this just --
3 your submitting on the only the single item
4 global rating for the performance measure.

5 DR. ERSEK: Right.

6 DR. PACE: So we don't have a
7 reliability at the data element level, which
8 we could talk about. But we also didn't see
9 anything for the performance measure level.

10 DR. ERSEK: Okay.

11 DR. PACE: So the computed -- so
12 each patient gives a global rating and
13 according to your specification this is -- all
14 the patient data is aggregated. I believe
15 it's an average.

16 DR. ERSEK: Correct.

17 DR. PACE: Or top box. I don't
18 remember. But the point is did you do any
19 reliability testing for those computed
20 facility scores?

21 DR. ERSEK: We did --

22 DR. PACE: Like a signal --

1 DR. ERSEK: Well, if you're
2 talking about the Cronbach's alpha, you are
3 correct. And I apologize for that. For us in
4 the VA it's hard to disentangle the one item
5 from the rest of the BFS, because we use it
6 all even though the performance measure is
7 technically only the single item.

8 We have run -- when you say
9 reliability, it wasn't -- so test-retest, no,
10 we've not done test-retest. And I guess I
11 would ask what would be appropriate, and what
12 would be gained from that? We did do splits
13 -- where is it -- I'm sorry -- split half
14 reliability testing. And I can send you these
15 results, but basically we separated our sample
16 of about 40,000 randomly. The means for both
17 of those groups were 59 and 59, so right on.
18 They were the same.

19 DR. PACE: And that was for the
20 overall rating?

21 DR. ERSEK: Yes.

22 DR. PACE: Okay.

1 DR. ERSEK: Yes.

2 DR. PACE: So that --

3 DR. ERSEK: They're global items.

4 DR. PACE: Right. Okay. So that
5 could be reliability of the data element
6 level, split half.

7 DR. ERSEK: Yes.

8 DR. PACE: But the next question
9 is then for the computed score do you have
10 reliability testing, which would be how you
11 actually compute the facility scores. So when
12 you compute a facility score, is it the
13 average or is it -- let's see. Okay. It's
14 based on the optimal response. So it's the
15 percentage of patients who --

16 DR. ERSEK: Yes.

17 DR. PACE: -- chose the optimal
18 response?

19 DR. ERSEK: Well, their family.
20 So we have an overall score --

21 DR. PACE: Right, right, right,
22 right. Sorry.

1 DR. ERSEK: Yes, I know. On the
2 overall score the choices are excellent, very
3 good, good, fair, poor.

4 DR. PACE: Right.

5 DR. ERSEK: We dichotomize that
6 into excellent, and everything else.

7 DR. PACE: Right.

8 DR. ERSEK: And so the report at
9 the individual and the facility level is the
10 percentage of people or families of that
11 facility who reported the care as being
12 excellent.

13 DR. PACE: Okay. So that's what
14 we're asking, if you've done any reliability
15 analysis such as signal-to-noise for that
16 computed facility-level score, the percentage
17 of patients who rated the care -- or families.
18 I'm sorry. Percentage of families who rated
19 their family member's care as high, or
20 excellent.

21 DR. ERSEK: No, not to date.

22 DR. PACE: Okay. So, again, we

1 would be in the same situation that we were
2 with the care instrument in terms of your
3 rating, but there's one caveat here. I mean,
4 you have all the data. It's probably
5 something that you could do. So perhaps we
6 could talk with you afterwards and we can
7 think about how to -- yes. So why don't we go
8 ahead -- if --

9 CO-CHAIR MERLINO: Any other
10 questions or comments?

11 DR. PACE: How about Deb and the
12 other reviewers for the reliability, if you
13 have any thoughts? Len or Deb or Don,
14 anything to add to that?

15 MEMBER SALIBA: The only
16 additional thought is to try to be a little
17 bit clearer that this is for veterans that die
18 in the hospital at this point.

19 DR. ERSEK: Yes.

20 MEMBER SALIBA: It's not for all
21 end of life vets.

22 CO-CHAIR MERLINO: Right.

1 DR. ERSEK: Correct.

2 MEMBER SALIBA: But that's --

3 DR. ERSEK: Currently.

4 MEMBER SALIBA: Yes. But
5 otherwise no other comments.

6 MEMBER PARISI: The other comment
7 that I would make is the same thing, that it's
8 specific to the VA system, but also not the
9 same as the FEHCs, whereas it just looks at
10 end of life care, not specific to hospice,
11 which I believe is a variation from what I'm
12 reading.

13 CO-CHAIR MERLINO: Any other
14 comments?

15 DR. PACE: I mean, this one is end
16 of life care, right?

17 MEMBER PARISI: Yes, versus
18 hospice care.

19 DR. ERSEK: And also the
20 inpatient. I think it's easy to think about
21 inpatients being acute care and intensive
22 care. We can actually break down our findings

1 or our results. It also includes our hospice
2 and palliative units, some of which have
3 patients there for many months, because ours
4 are run differently than Medicare --

5 CO-CHAIR MERLINO: Okay.

6 DR. ERSEK: -- inpatient units.

7 CO-CHAIR MERLINO: Any other
8 comments?

9 DR. ERSEK: The other thing is
10 TLC.

11 CO-CHAIR MERLINO: Any other
12 comments from the Committee? Questions?
13 Okay. Let's vote on reliability.

14 MS. ALLEN: So we're voting on
15 reliability and it includes precise
16 specification and testing. One, high; two,
17 moderate; three, low, and four, insufficient.
18 Starting the clock now.

19 All votes are in. Zero high,
20 seven moderate, four low, and seven
21 insufficient.

22 DR. PACE: So this would stop

1 here. And just so that we kind of do a check
2 on where people are in terms of the moderate
3 rating, did that mean that you all wanted --
4 those who voted moderate wanted to proceed,
5 even though they hadn't done the testing at
6 the performance score level? Okay. All
7 right. Just wanted to --

8 (Simultaneous speaking.)

9 DR. ERSEK: Can I just -- so
10 specifically the test you're looking for,
11 because reliability is kind of broad, you were
12 looking for noise-to-signal analysis?

13 CO-CHAIR MERLINO: We'll take that
14 discussion offline, because we're running a
15 little bit behind schedule.

16 DR. ERSEK: Okay.

17 DR. PACE: We'll talk to you
18 afterwards, because I think you do have the
19 data that you could do that, and provide that.
20 So we'll definitely work with you.

21 CO-CHAIR MERLINO: Okay.

22 CO-CHAIR PARTRIDGE: So that

1 brings us to lunch time.

2 MS. DORIAN: First, before that
3 we're just going to do a quick check-in with
4 the operator to see if there are any --

5 CO-CHAIR PARTRIDGE: I'm sorry.

6 MS. DORIAN: -- public comments.
7 So, operator, if you could please open the
8 lines for public comment?

9 OPERATOR: And if there are any
10 public comments, please press star one on your
11 telephone keypad.

12 And there are no public comments
13 at this time.

14 MS. DORIAN: Is there anybody in
15 the room who would like to make a comment?

16 DR. JAMES: Thank you. Tom James.
17 I'm the chair of the Health Plan Council for
18 NQF, and a member of the public here.

19 First, I want to congratulate you
20 on a lot of very lively discussion here. This
21 is an important topic. I was on the Dual
22 Eligibles Work Group. The hospice criteria

1 and measures we adopted in that were all
2 procedural ones. I think it is important to
3 be able to have lines of patient and family
4 experience to supplement that. I know that
5 we're going in the right direction. We want
6 to get good measures, but I think that that is
7 going to be key. And I'd love to see that go
8 back to the Dual Eligibles Work Group. Thank
9 you.

10 MS. DORIAN: Thank you. And
11 before we break for lunch, I did also just
12 want to do a quick poll to see who would be
13 interested in attending dinner tonight at 6:00
14 p.m. Anybody? It's about two blocks from
15 here. It's Mio. It's on Vermont. And I can
16 put the directions up.

17 DR. PACE: Do you want them to
18 sign up?

19 MS. DORIAN: No, no, no. I just
20 wanted to get a head count, and then I'll put
21 some information up on the screen at the end
22 of the day so you can find it. Okay. All

1 right. We'll see how everybody's feeling.

2 DR. PACE: Well, just come up and
3 let Lauralei know --

4 MS. DORIAN: You can let me know,
5 yes.

6 DR. PACE: -- during the lunch
7 break.

8 CO-CHAIR PARTRIDGE: I suspect
9 that many of us did as I did, and didn't think
10 there was going to be a group dinner and make
11 alternative plans. But for the future it is
12 kind of fun to get together, so we'll keep it
13 in mind.

14 MS. DORIAN: Great.

15 MEMBER THOMAS: Quick comment
16 about public comment. It strikes that before
17 we take the final vote on a measure, it would
18 probably be a lot more meaningful to get the
19 public comment then, before voting. And then
20 if someone wants to say something about that
21 measure, the vote has already been taken, it's
22 largely water under the bridge. So is the

1 purpose of the public comment to get the
2 public's view on these measures before we
3 finalize our vote, or is it just if something
4 comes up that they'd like to bring to our
5 attention, generically?

6 DR. BURSTIN: It's a good
7 question, Peter. It's probably more the
8 latter for this point for public comment, but
9 public comment will be much more significant
10 following the draft report that goes out for
11 comment.

12 MEMBER THOMAS: Okay.

13 DR. BURSTIN: People can submit
14 online comments at that point. And keep in
15 mind they can submit comments on measures you
16 recommended, also measures you didn't
17 recommend or any measures in the gray zone.
18 So you'll get, potentially, the opportunity.

19 Anything you may have in fact said
20 no to today, you could get a groundswell that
21 puts additional information forward, including
22 from the developers that could change your

1 mind. So this is still pretty early in the
2 consensus process. So you usually get pretty
3 minimal comments at an in-person meeting, but
4 much more to follow.

5 MEMBER BEVANS: I know we're all
6 anxious to go to lunch, but we're making a
7 recommendation for approval, but what happens
8 next? How does the approval process actually
9 happen and integrate the public comment?

10 DR. BURSTIN: Right, so what will
11 happen is is when we get the public comments
12 back, we'll set up a post-comment call with
13 all of you to review them. The comments will
14 be themed by staff. You'll have an
15 opportunity to see if there's any measures you
16 want to revisit prior to a final report going
17 out for vote. It will then go to our
18 Consensus Standards Approval Committee that
19 reviews all the final measures recommended.
20 Actually Lee sits on that Committee. So
21 you'll have an in-house rep there. And then
22 ultimately to the Board for ratification.

1 And since we know this group will
2 be ongoing in other phases, you'll have lots
3 more opportunity to revisit. Even some of the
4 measures that perhaps just needed more work
5 could potentially even come back in later
6 cycles.

7 DR. PACE: Okay. Thank you. So
8 we have a buffet set up. We'll try to get
9 back to our seats at 1:00. You can eat back
10 there or bring your lunch to your seat, but
11 we'll reconvene at 1:00.

12 (Whereupon, the above-entitled
13 matter went off the record at 11:30 a.m. and
14 resumed at 1:00 p.m.)

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A-F-T-E-R-N-O-O-N S-E-S-S-I-O-N

(1:00 p.m.)

MS. DORIAN: Okay, everyone, we're about ready to get started again. I hope you enjoyed your lunch.

Our next slotted item was going to be competing measures and harmonization, but we actually will skip over that because two of the measures in that discussion did not move forward earlier on, so we gain a little bit of time that way.

So we're moving on to 0258, which is the CAHPS In-Center Hemodialysis Survey from CMS. And we have the developers. If you'd like to introduce yourself.

MS. CRAWLEY: Good afternoon. I'm Barbara Crawley and I'm here for 0258, the In-Center Hemodialysis CAHPS Survey.

MS. GOLDSTEIN: And I'm Liz Goldstein. I'm from CMS, and under my division at CMS is the In-Center Hemodialysis Survey, the Home Health Care CAHPS Survey and

1 the Hospital CAHPS Survey.

2 Well, also there was a lot of
3 discussion about the Hospice CAHPS Survey this
4 morning and so the development of that survey
5 has been completed. So we will be submitting
6 it next time there's an opportunity to submit.

7 MS. DORIAN: Great, thanks. And
8 if one or the other of you would like to give
9 a brief introduction to the measure.

10 MS. CRAWLEY: Like all the CAHPS
11 surveys, the In-Center Hemodialysis Survey
12 stresses standardization, beginning with the
13 training of our survey vendors, letting all of
14 the facilities know that this is going to take
15 place from a protocol that is standard across
16 all of the process. And this is our training
17 manual. This is our manual. This is our
18 protocol and every CAHPS survey has a protocol
19 that must be followed.

20 Even with the data submission of
21 the survey results, it's all done in a
22 template that must be submitted to CMS in that

1 format.

2 As the first CAHPS survey to
3 address the experience of a specific patient
4 population, the results from the ICH CAHPS
5 work will address accountability for dialysis
6 centers, drive quality improvement and provide
7 performance measures for quality measures.
8 And we hopefully will start seeing public
9 reporting in 2016.

10 Currently the data that we have is
11 based on the pilot testing that was done back
12 in 2005. There are 5,800 dialysis centers
13 with nearly 370,000 patients with permanent,
14 irreversible kidney failure.

15 What we have out on the CMS
16 website right now as far as quality data has
17 to do with the clinical information
18 surrounding dialysis care. There is nothing
19 about the provider-patient interaction or the
20 communication that goes on within a dialysis
21 facility to assist the patient about
22 information that they will receive over the

1 course of time.

2 One of the questions that just
3 came from a facility that they want to add to
4 the current survey, which they're allowed to
5 do, is how warmly were the patients greeted
6 when they first arrive at the center. So
7 there is some interest, even at the facility
8 level, about communication.

9 We have talked a lot about the
10 interaction between the patients and the staff
11 and we know that Medicare does have
12 regulations that require dialysis facilities
13 to implement a process for beneficiaries to
14 file grievances. But what we've learned is a
15 lot of times patients do not file these
16 grievances. They may not know about the
17 avenues that they have, or a lot of them fear
18 their airing of their problems.

19 So a lot of our questions do
20 address problems that they may encounter in
21 the survey about communicating those problems.
22 And I'll stop there, so you can ask questions.

1 MS. DORIAN: Great. So just to
2 remind everybody who the reviewers of this
3 measure were, we have, for importance, Becca
4 Bradley, Carol, Lisa, Lee and Peter. And then
5 for scientific acceptability, Sam, Dawn,
6 Sherri, Len and Deb.

7 MEMBER BIERNER: Can I ask
8 something?

9 MS. DORIAN: Sure.

10 MEMBER BIERNER: Just want to ask
11 the developers, the issue of this reluctance
12 of the patients to give adverse information or
13 negative information, how has that played out?
14 How are you monitoring that? Is there some
15 way you've established that you're getting
16 reliable responses, or at least in the format
17 of your outcome measure?

18 MS. CRAWLEY: Well, in the
19 protocol, the survey may not be administered
20 within the facility. It has to be done by a
21 third-party vendor who will contact the
22 patient directly, either by one of three

1 modes, mail only, mixed mode, which is mail
2 followed by telephone, or telephone-only mode.

3 We do have a question on the
4 survey that asks, did anyone assist you with
5 this, filling out the questionnaire? And we
6 will eliminate those questionnaires where it
7 said someone at the facility assisted.

8 MEMBER BIERNER: If they have a
9 physical handicap that they need assistance,
10 that's not disallowed?

11 MS. CRAWLEY: That's not
12 disallowed if it needs to be translated into
13 a language that we have not standardized thus
14 far. We have it in English, well, Spanish,
15 Chinese and American Samoan right now, because
16 there is a couple facilities in American
17 Samoa.

18 CO-CHAIR PARTRIDGE: But I think,
19 according to my notes from our work group
20 call, am I not correct, this is a situation in
21 which you got a special protocol and you pull
22 the sample and you notify the patients, Liz?

1 MS. GOLDSTEIN: Yeah, so for this,
2 for some of our surveys, the provider provides
3 a discharge list or current patient list to
4 the survey vendor.

5 For this survey, when we get to
6 national implementation this fall, CMS is
7 pulling the sample. So we want the provider
8 totally separate from the survey process.

9 We also, for this survey, because
10 we knew of some of the concerns, we did over
11 the winter a lot of testing of our cover
12 letter with ESRD patients to make sure we're
13 giving them any reassurances they need in that
14 cover letter.

15 CO-CHAIR PARTRIDGE: So I think
16 that, as I heard that, one of the questions
17 for this committee to think about is, is that
18 protocol a specific part of the specifications
19 for this measure? Because, as I recall, you
20 were extremely concerned about whether
21 patients would be comfortable responding.

22 MS. GOLDSTEIN: I think, for us,

1 yes. I think for the -- and I'll maybe make
2 this point now, but I think it's the same for
3 the ICH CAHPS Survey, Home Health Care CAHPS
4 Survey and the Hospital CAHPS Survey we're
5 talking about today.

6 We have, for all three surveys,
7 very standardized protocols. And NQF had
8 given us guidance. We don't need to go
9 through all our specifications. We should
10 refer to what we have online on our various
11 websites.

12 So for all of our surveys, we
13 would say our full protocol, which are in
14 these thick manuals, is our specification.
15 I think as we, CMS, has implemented surveys
16 nationally, we have found that, you know, just
17 giving measure specifications and questions
18 are not sufficient to ensure standardization
19 of a measurement.

20 So I would have great concern, you
21 know, just implementing it from a survey
22 without sampling protocols. When you do the

1 survey. What's a telephone complete? What's
2 a call attempt?

3 Our things are very, very, very
4 specific, much more specific than what we've
5 been talking about earlier today. And so
6 those really are part of our specifications.

7 DR. PACE: And NQF would consider,
8 as you saw, that those were items in the
9 specifications, sampling and survey
10 instructions.

11 Because of the voluminous manuals,
12 we didn't want them to copy and paste that
13 into the submission form, and suggested that
14 they could put, you know, kind of some key
15 points in the submission form and refer to the
16 manual.

17 So there's only so much that
18 everyone can handle here. But we definitely
19 consider sampling and survey part of
20 specifications.

21 So maybe we can get on to 1A, the
22 evidence. And, again, this is about are there

1 interventions, services, actions by the, in
2 this case, the dialysis facility that will
3 influence the experience with care?

4 And those of you who reviewed this
5 part of the measure may want to make some
6 comments. Microphone, please.

7 MEMBER BRADLEY: Since dialysis is
8 being provided now in multiple settings,
9 patients are coming in as outpatients, some
10 are receiving dialysis as units in a hospital,
11 is there any variation or is that risk
12 adjusted in any way? Are you looking at the
13 experience based on the setting of where the
14 dialysis is occurring?

15 MS. CRAWLEY: Part of the protocol
16 is that our inclusion criteria, it must take
17 place in a in-center hemodialysis center as an
18 outpatient.

19 If you're having acute condition
20 and you're already on dialysis and you must
21 continue dialysis while you're in the
22 hospital, you will not be selected for the

1 survey. So it's only patients receiving in-
2 center hemodialysis care as an outpatient.

3 MEMBER PARISI: That actually
4 answers my question, because I was actually
5 enthusiastic that this would be a first
6 measure that would measure care across the
7 continuum, but that's not the case.

8 But it is only reflective of a
9 population with a diagnosis of ESRD, is that
10 correct? And the sample will be selected, I'm
11 assuming, based on the CMS criteria for billed
12 visits for dialysis? Is that correct?

13 MS. CRAWLEY: Well, they have to
14 have been at a outpatient center for three
15 months or more to be selected. They have to
16 have end-stage renal disease. They have to be
17 18 years or older.

18 If you're in a nursing home and
19 you're receiving dialysis care where you're
20 going outside of the nursing home to have
21 that, we're excluding those patients because
22 we feel as though they'll be confused about

1 their care, whether it's nursing home care
2 versus the dialysis care.

3 MEMBER PARISI: So it's
4 ambulatory?

5 MS. CRAWLEY: Absolutely.

6 DR. PACE: So any comments about
7 the influence of the dialysis facility on the
8 experience that's being measured?

9 MEMBER THOMAS: Correct me if I'm
10 wrong, but the vast majority of ESRD treatment
11 is performed in hemodialysis centers on an
12 outpatient basis. It's something like over 90
13 percent or something, right?

14 MS. CRAWLEY: That's correct.

15 MEMBER THOMAS: Peritoneal
16 dialysis is the other major method and that's
17 relatively small.

18 MS. CRAWLEY: A small percentage.

19 MEMBER THOMAS: So we're getting
20 to the vast bulk of those patients and
21 measuring it.

22 MS. CRAWLEY: Absolutely.

1 MEMBER THOMAS: Is there a reason
2 why, and did I miss this in your introduction,
3 is there a reason why we need to substitute
4 our judgment for the tie between whether this
5 impacts a structure, process, intervention or
6 service?

7 DR. PACE: Oh, that was my note
8 based on what was actually provided in the
9 submission form. So they provided some
10 information about the types of content that
11 was included in each of the performance
12 measures and discussed some general healthcare
13 actions.

14 And so the question to the
15 Committee, because they didn't do kind of a
16 one-to-one, is are you satisfied that the
17 dialysis facility can influence these?

18 MS. GOLDSTEIN: You know, we could
19 add something to that. For all the CAHPS
20 surveys, the patient experience items are all
21 -- I mean, that's part of the development of
22 the survey -- are all things that the provider

1 has control over and they're all things that
2 come from the patient, things that they
3 express to us that they want information
4 about.

5 So the items that we included on
6 all these surveys are things where the patient
7 is the best or only source of information.
8 How the survey is developed, all the items are
9 things that a provider can influence.

10 DR. PACE: And I think for these,
11 you know, the questions that go with a
12 performance measure are kind of indicative of
13 the things that the provider can do. But, you
14 know, it is just a question to the committee
15 if you agree.

16 MEMBER LEVINE: Since the pilot,
17 am I right, the pilot data was collected 2005?

18 MS. CRAWLEY: That's correct.

19 MEMBER LEVINE: And it's 2014. Is
20 there a reason why it took so long? Or is
21 there any reason to think that that pilot data
22 might be outdated in any way?

1 MS. GOLDSTEIN: I think the survey
2 was developed a number of years ago, and
3 there's been a lot of discussions within CMS
4 for a number of years about moving to national
5 implementation. Some of it had to do with
6 budget issues and, you know, different
7 priorities.

8 But CMS, right now, we have a huge
9 emphasis on developing and implementing
10 patient experience of care surveys, so we have
11 a number of additional ones we're currently
12 developing.

13 So as part of this, you know,
14 increased emphasis on patient experience,
15 there was a decision to move forward with
16 national implementation of this survey.

17 The data that we're submitting to
18 NQF at this point is the same data we
19 submitted in our original endorsement. We're
20 not going to have new data until January 2015
21 with the first administration of the survey
22 with reporting to CMS.

1 Over the last couple years,
2 facilities have been required to use the
3 survey, but to do it on their own, not using
4 approved vendors, the protocols haven't been
5 so rigorous and they did not have to submit
6 the data to CMS.

7 MS. ALLEN: We're starting the
8 vote on evidence. Rationale supports the
9 relationship of the health outcome, or PRO, to
10 at least one health care structure, process,
11 intervention or service. One for yes, two for
12 no. The timer starts now.

13 The vote is in. Eighteen yes,
14 zero no.

15 DR. PACE: Okay, let's move on to
16 performance gap, 1B. And this can be
17 performance gap at the facility level or
18 disparities.

19 MEMBER SALIBA: So I'm on the
20 post-acute care/long-term care NQF panel and
21 we have been looking at measures in the area
22 of dialysis, and there is a huge, huge, huge

1 need for measures focused on this population.
2 They're very vulnerable. They're at very high
3 risk for -- they have multiple, as it says in
4 the documentation that was provided, they have
5 multiple comorbidities, often some cognitive
6 impairment.

7 So this is a really important area
8 where there are huge gaps across dialysis
9 centers and providers in terms of the quality
10 of care that's being provided.

11 MEMBER THOMAS: With respect to
12 disparities, my understanding is that this
13 population is very disproportionately minority
14 population. Is that correct?

15 MS. CRAWLEY: Yes, that's true.
16 When we think about the comorbidities that
17 exist in this population, the diabetes, heart
18 disease, those are conditions that you find
19 predominantly in African American community.

20 MEMBER THOMAS: So --

21 MS. CRAWLEY: If you look -- I'm
22 sorry. Go ahead.

1 MEMBER THOMAS: So the fact that,
2 reading in some of the notes that have been
3 prepared by staff that there is no data on
4 disparities in the experience of care, but
5 isn't just collection of the data itself
6 reflective of a fairly significant portion of
7 African Americans being sampled, correct?

8 MS. CRAWLEY: Right. I think in
9 our results from the pilot testing we had
10 about 40 percent African American, 40 percent
11 white and the rest other.

12 So we did not sample by race,
13 ethnicity, but we captured, say, 40, you know,
14 probably an even split between African
15 Americans and whites.

16 MEMBER THOMAS: Just by virtue of
17 the population?

18 MS. CRAWLEY: Just by virtue of
19 the population.

20 CO-CHAIR PARTRIDGE: I'm sorry, I
21 should have asked. This is an all-payer, am
22 I right? This is not just Medicare patients?

1 MS. CRAWLEY: It is from centers
2 who are --

3 CO-CHAIR PARTRIDGE: Medicare-
4 certified, but it's their entire caseload?

5 MS. CRAWLEY: Right, 18 years old
6 and older.

7 CO-CHAIR PARTRIDGE: I'm a former
8 state Medicaid director so I suddenly thought,
9 oh, if you get current data, you're going to
10 get a lot more Medicaid patients in there.

11 MEMBER THOMAS: Are you talking
12 about the high percentage of Medicare
13 beneficiaries who are ESRD?

14 CO-CHAIR MERLINO: Yeah, I was
15 just saying that I think most end-stage renal
16 disease is Medicare, right? That's one of the
17 few --

18 CO-CHAIR PARTRIDGE: It makes you
19 eligible for Medicare. There are people who
20 are not Medicare eligible.

21 DR. PACE: So we don't have
22 performance data on the measure as specified

1 in the section, but the question is, you know,
2 obviously, as Deb Saliba was mentioning, this
3 is an area that's thought to have areas for
4 improvement, and I guess see if anyone has any
5 other specific questions or comments to add to
6 that before you move on to voting.

7 (Pause.)

8 MS. ALLEN: So we're voting on
9 performance gap data demonstrated considerable
10 variation or overall less than optimal
11 performance across providers and/or population
12 groups. One high, two moderate, three low and
13 four insufficient. Starting the votes now.

14 All votes are in, ten high, seven
15 moderate, one low and zero insufficient.

16 DR. PACE: One thing I want to
17 just remind everybody about now as we continue
18 on, and I should have said this at the
19 beginning, this is not one measure and we're
20 not endorsing the survey.

21 So there are six performance
22 measures that you're actually looking at here.

1 So it's nephrologist communication and caring,
2 the quality of dialysis center care and
3 operations, providing information to patients.
4 And then three global items: rating of the
5 nephrologist, rating of the center staff and
6 rating of the facility.

7 So just keep in mind as we're
8 going through this and start getting specific
9 information about those individual performance
10 measures, that if there's any one in
11 particular that you have a question about, you
12 know, we can discuss that.

13 But if not, we'll vote on them
14 kind of en bloc. But just wanted to call that
15 to everyone's attention because we've kind of
16 switched now into these submissions that have
17 multiple measures.

18 CO-CHAIR PARTRIDGE: Karen, just
19 to be clear, if you think that one of these
20 measures is either very strong or very weak
21 and you wanted to vote on it individually, we
22 can pull it out and we can do that.

1 DR. PACE: Yes.

2 CO-CHAIR PARTRIDGE: Okay.

3 DR. PACE: Let's go on to high
4 priority. I think we've had a little bit of
5 this discussion already in terms of the
6 patient population and some of their
7 characteristics.

8 And the submission, I believe,
9 talked about using focus groups and the
10 developers here have also mentioned that. So
11 comments or questions?

12 CO-CHAIR MERLINO: Anybody
13 disagree that this isn't high priority?
14 Should we just go to vote? Let's go to vote.

15 MS. ALLEN: So we're voting on
16 high priority. One is high, two moderate,
17 three low and four insufficient. Starting the
18 vote now.

19 We're still missing a vote. Thank
20 you.

21 All votes are in. Results show 17
22 high, one moderate, zero low, zero

1 insufficient.

2 DR. PACE: Okay, we'll move on to
3 reliability, which includes the specifications
4 and reliability testing at the scale or
5 patient-level measure score and the computed
6 performance score for the dialysis facility.

7 CO-CHAIR MERLINO: How many
8 facilities in the United States do you
9 estimate?

10 MS. CRAWLEY: 5,800 approximately.

11 MEMBER THOMAS: There were some
12 red flags that kind of went off a little bit
13 in this one, like in terms of reliability,
14 like I guess the vulnerability of the
15 patients, the statement a few times that many
16 of these patients have significant cognitive
17 limits, a number of them fear retribution in
18 terms of sampling what they think of their own
19 care, a number feel that they're lucky to be
20 in a facility that has a time slot available
21 that's maybe close to their house and if they
22 complain maybe they wind up losing that and

1 wind up being sent across town.

2 And so how would you say that
3 really impacts reliability of the data that
4 was collected?

5 MS. GOLDSTEIN: I think how we've
6 set up the protocols are to ensure that
7 patients feel that they can answer the
8 questions honestly.

9 Even from the field test, you
10 know, a number of years ago, and Barbara and
11 I worked on that field test many, many years
12 ago, but there we felt like patients were
13 honest. The scores, there was a lot of
14 variation across, you know, facilities.

15 So people were not afraid to speak
16 up, I think, as long as they're reassured that
17 their responses aren't going straight back to
18 the facility and the facility is going to act
19 upon those responses.

20 So I think as long as the
21 protocols are set up, they're rigorous and,
22 you know, the patient feels comfortable and we

1 make them comfortable in responding, I think
2 they will, you know, answer honestly.

3 CO-CHAIR MERLINO: Any other
4 comments?

5 MEMBER DOWDING: I've just got a
6 question. I'm going through the data on
7 reliability and I can see the reliability for
8 the three composite measures. But do you have
9 any data on the three global measures? That
10 seems to be missing in our submission, either
11 that or I can't see it.

12 MS. GOLDSTEIN: No, it is missing.
13 So Barbara and I were not the ones who
14 submitted this original package years ago. So
15 we also realized that that was missing from
16 this submission.

17 So we had to track down who still
18 has access to these data, because we do not
19 have access to it. We have tracked that down
20 and we will have the facility-level
21 reliability for those three global ratings
22 later this week.

1 So I think NQF said, to at least
2 some of my staff last week, that if we have
3 additional information we could submit it in
4 August.

5 DR. PACE: Yeah. What we'll do
6 is, you know, if there was additional
7 information, I don't know if you have anything
8 to report on that verbally, but there's a
9 couple of things then.

10 One is, you know, whether that
11 causes any concern in terms of moving this
12 forward based on the information you do have,
13 or you can go ahead and vote on this and they
14 can submit it. During the comment period is
15 usually the time that we can gather any
16 additional information that's needed to
17 supplement what was already submitted.

18 So, you know, what we identified
19 here is the -- this is for the three scales,
20 as Dawn was mentioning, and the ICHR is the
21 facility level, the performance score level
22 reliability. And then the last column, alpha,

1 is the scale level, the patient level scale,
2 and all these statistics are good.

3 And I don't know if you have any
4 general comments, or know anything about those
5 others that you want to comment on or just --

6 MS. GOLDSTEIN: I think we have to
7 wait til later this week. What we have access
8 to is information, for example, the
9 communication one, the overall rating. Right.
10 That one about ten percent are rating kind of
11 near that top box but there's a lot of
12 variation. The other ones we know from the
13 information that we have they're not topped
14 out at all. Very few are weighing up high but
15 we'll have more information later this week.

16 CO-CHAIR PARTRIDGE: Katherine.
17 No, I'm sorry, Dawn.

18 MEMBER DOWDING: Yes, it's just a
19 query. I don't know if I'm comfortable voting
20 on three measures for which we don't have any
21 reliability or validity data. It's just a
22 personal thing. I'm quite comfortable voting

1 on the data, for the data we have, given that
2 these are six measures, not one composite.

3 DR. PACE: That's fair, and we can
4 deal with the other three when we have that
5 information.

6 So if you want to comment on the
7 reliability data that we do have for these,
8 you'll see that, the In-Center, .64, .51 and
9 .53, which are a little lower than the CAHPS
10 usually likes. And, again, this is pilot data
11 so I don't know if Barb or Liz want to make
12 any comments about that or your thoughts about
13 that.

14 MS. GOLDSTEIN: Yeah, I mean, one,
15 this is pilot data so it's off of a small
16 number of facilities, only 32. So these are
17 the types of statistics that we regularly run
18 on all of our data. So, you know, we'll re-
19 run these again obviously when we get data in
20 January and there'll be obviously a lot more
21 data.

22 DR. PACE: So, you know, I'll just

1 put this in perspective. You know, so this is
2 similar to what we would see for an initial
3 endorsement, and for various reasons this was
4 delayed getting implemented.

5 It's a reason that, you know, if
6 this were the, you know, second time it came
7 up we would like to see more robust
8 information. But I think you should maybe
9 kind of think of it in the perspective as you
10 would an initial, you know, endorsement.

11 CO-CHAIR MERLINO: Peter.

12 MEMBER THOMAS: I have a question
13 about one of the last things on some of the
14 staff prepared notes. It says that this is
15 due to be implemented for payment programs,
16 meaning the ESRD Medicare payment program, in
17 2014 and '15.

18 So regardless of what happens to
19 these measures in this process, is CMS going
20 to be implementing this nonetheless? Or will
21 this make it dependent upon whether they do
22 that?

1 MS. GOLDSTEIN: CMS is moving
2 forward with implementation. So there have
3 been, in prior rules for prior years, there's
4 been information about how facilities needed
5 to do the survey on their own, not reporting
6 to us. So that's already happened for two
7 years.

8 And for 2014, facilities are
9 required to collect this information. So
10 it'll be the fall of this year. So we are
11 moving forward, you know, with data
12 collection. So it's not contingent on this
13 endorsement.

14 MEMBER THOMAS: So the only
15 distinction there then would be that CMS would
16 move forward with a measurement tool that is
17 not approved by the NQF. But they're still
18 moving forward with it. Am I right?

19 MS. GOLDSTEIN: Correct.

20 MEMBER THOMAS: All right, thanks.

21 DR. PACE: Right. So generally
22 CMS likes to utilize NQF-endorsed measures,

1 but they also have mechanisms to proceed when
2 they need to.

3 But basically, you know, the
4 Committee votes on the measures and the
5 information that's presented, and then, you
6 know, we try to sort things out as we go
7 forward.

8 So I think, again, that's why I
9 wanted to say, I think you need to think about
10 this in the perspective of almost like an
11 initial endorsement because it's still kind of
12 the pilot testing data, and is it sufficient
13 to move it forward for implementation?

14 And then, you know, in the next
15 endorsement maintenance, have much wider
16 implementation and data to say, well, you
17 know, this hasn't improved. What's going on?
18 Or see what the difference is as we have wider
19 implementation.

20 CO-CHAIR PARTRIDGE: Carol.

21 MEMBER LEVINE: I'm still
22 concerned about the question Peter raised

1 about the protocol and how it reassures the
2 patients that they're actually -- the
3 information is not going to be used against
4 them.

5 And I'm wondering if there is any
6 provision for staff training or who is -- if
7 it's mail, I mean, some of these people are
8 not going to be able to fill out something.
9 Is it phone call? Is there training about how
10 the facility tells the patient that you may be
11 getting this questionnaire, this survey?

12 There's a lot of pressure. A lot
13 of these, maybe most of these dialysis centers
14 are for-profit centers and there's a lot of
15 pressure to look really good. And there's
16 just every incentive to make the results look
17 good unless there's a counterbalance that
18 says, you know, you have to reassure these
19 patients. I may be making things up except
20 that I hear all this stuff.

21 DR. PACE: Let's let the developer
22 respond to that.

1 MEMBER LEVINE: Thanks.

2 MS. GOLDSTEIN: So the facility,
3 besides contracting with a CMS-approved survey
4 vendor, is not involved at all in survey
5 administration procedures. So there's a set
6 of approved survey vendors. How many do we
7 have?

8 MS. CRAWLEY: Twenty-two.

9 MS. GOLDSTEIN: Twenty-two for
10 this program, and these 22 vendors have been
11 trained by CMS on all the protocols. These
12 trained vendors will have 800 numbers, so if
13 a patient gets a survey and doesn't know what
14 to do, they will call these 800 numbers, which
15 is going to a survey vendor and not to the
16 facility.

17 So the facility could, and they're
18 allowed to, let patients know they may be
19 getting a survey, but that's it. That's the
20 only interaction that the facility has with
21 the patients over the survey results.

22 The facility will not get the

1 individual-level survey results back. They
2 will get aggregate data. They can get it by
3 patient characteristics as long as -- even by
4 patient characteristics it's not enough to
5 identify, you know, who a patient is. So cell
6 sizes have to be, you know, 11 or more if
7 we're doing, like, a cross tab by
8 characteristics and responses.

9 So there's a lot of protocols that
10 are set so the facility can never identify
11 how, you know, Mrs. Jones responded on the
12 survey.

13 MEMBER LEVINE: It would be good
14 to have that kind of information in the
15 submission. I don't think it was as
16 completely as you've described it.

17 DR. PACE: So I'll just jump in
18 here and explain that, you know, that's part
19 of what we were talking about before. They
20 have, you know, a very extensive protocol.

21 And this is something we can talk
22 about tomorrow when we get to your feedback

1 and suggestions of, you know, if it's a 500-
2 page manual, we can't have that copied and
3 pasted into the submission form. And what's
4 the best way, you know, what are the key
5 things to communicate?

6 So, you know, definitely there's
7 pros and cons and a myriad of ways and
8 definitely think about that and if you have
9 some suggestions so that we can talk about
10 that tomorrow, because it's a challenge for
11 these surveys that have very extensive
12 protocols. Okay, so, Jim.

13 CO-CHAIR MERLINO: Any other
14 questions? Sorry.

15 CO-CHAIR PARTRIDGE: Lisa.

16 MEMBER MORRISE: So I am just
17 wondering if we, as a body, should be
18 consistent in the application of the standards
19 that have been set up from one to another.

20 And this particular effort, though
21 certainly significant, does not have the data
22 for the individual centers, right -- or the

1 centers. It's for the individuals only. Is
2 that correct?

3 DR. PACE: No, what we have here
4 is the patient-level data and the center-level
5 reliability statistics for three of the
6 measures that are based on multi-items.

7 So what's missing that we talked
8 about, and the developers mentioned, is for
9 the three global ratings they don't have it
10 right now but they can get it to us.

11 So I think one of the suggestions
12 was for the group to focus on the three
13 measures for which there is data and then
14 they'll come back to us with the other data.
15 Does that make sense?

16 CO-CHAIR PARTRIDGE: Karen, just
17 to clarify, I think, are we technically, from
18 the perspective of voting, setting aside
19 Measures 4, 5 and 6, which are the global
20 measures, and either not voting on them or are
21 we voting them insufficient today or low today
22 or --

1 MEMBER MORRISE: So should we, in
2 essence, as a body, vote on what we're voting
3 on?

4 (Laughter.)

5 CO-CHAIR PARTRIDGE: Yes, well
6 said.

7 DR. PACE: And maybe we can do
8 this by a show of hands. So let me just test
9 this out.

10 If you're in favor of kind of
11 splitting the question so that we have you
12 deal with the three measures for which you
13 have all of the data separately from the three
14 that we don't, if you're in agreement with
15 that, would you just raise your hand to kind
16 of split the question there?

17 (Show of hands.)

18 Okay, all right. So and maybe the
19 cleanest thing to do would be let's vote on
20 reliability based on the three that we have
21 the data.

22 And, you know, I guess we could

1 formally vote on the others, which would be
2 insufficient and would end for that right now.
3 And then they could come back with that.
4 Would that work for everybody?

5 So let's do reliability on the
6 three that are here. And these three have
7 testing at both levels. We've talked about,
8 you know, the pilot, that maybe these aren't
9 as high as you might see when it's fully
10 implemented, you know, but it is tested at
11 both levels.

12 So it would be eligible for a high
13 rating at both levels, or if you think the
14 statistics are maybe not as high as we would
15 like, moderate rating is fine and either of
16 those pass.

17 So I think -- we okay to vote? So
18 you're voting on the three measures for which
19 you have data on both levels.

20 MS. ALLEN: Reliability for three
21 measures that have data on both levels. One
22 high, two moderate, three low, four

1 insufficient. Voting starts now.

2 All votes are in. Five high, 13
3 moderate, zero low, zero insufficient.

4 DR. PACE: Okay, so now the
5 question is how we vote on the -- why don't we
6 just do a hand vote on that? Our software, we
7 can't switch measures in the middle, so that's
8 a little technical glitch but I think we can
9 do a hand count on the three that we don't
10 have the information. Go ahead.

11 CO-CHAIR PARTRIDGE: For the
12 record, we're voting on M4, 5 and 6, rating
13 the nephrologist, rating the staff and rating
14 the facility.

15 DR. PACE: Yes.

16 MEMBER THOMAS: And a vote for
17 insufficient would still allow the developers
18 to bring additional evidence in the same
19 cycle, as opposed to voting moderate and then
20 they do the same thing?

21 DR. PACE: Right. Insufficient
22 means that there's no data for you to rate it

1 against the criteria, which is where you're
2 at.

3 But we will have a period of time
4 during the public comment period where the
5 developers could submit that information so
6 that you could act on that after the comment
7 period. Does that make sense? Okay. All
8 right.

9 (Off microphone comment.)

10 CO-CHAIR PARTRIDGE: Well, that's
11 actually kind of what we're doing.

12 DR. PACE: We can do that. All
13 right, so maybe that'll be the -- why don't we
14 just use that as the vote then? Perfect.

15 CO-CHAIR MERLINO: We're going to
16 have the same problem with the other one.

17 DR. PACE: Well, this will stop
18 here.

19 CO-CHAIR MERLINO: For all six?

20 DR. PACE: No, just for the three,
21 just for three. Let's finish reliability and
22 then we'll --

1 CO-CHAIR MERLINO: On to validity.

2 CO-CHAIR PARTRIDGE: Right. Okay,
3 all in favor of deferring essentially. Okay.
4 Got that? Do you want to repeat it just into
5 the record?

6 DR. PACE: So, yeah, so actually
7 everyone voted in favor of deferring the three
8 overall rating measures until we receive that
9 testing data, the reliability data.

10 The rest of the criteria will
11 focus on the three measures based on the
12 multi-items, so we'll continue on to validity
13 now.

14 CO-CHAIR PARTRIDGE: Karen, I
15 don't want to slow you down.

16 DR. PACE: Okay. No, go ahead.

17 CO-CHAIR PARTRIDGE: But I think,
18 just to be fair to our developers in
19 particular, if anybody has some questions
20 about the validity issues or other issues
21 relating to those three global measures we
22 have deferred and there is information they

1 might bring back to us during the comment
2 period, I think we should try to raise it now.

3 For example, are you comfortable
4 with how the global measures are rated, the
5 top box method of scoring and so on? I'm not
6 saying there are issues here necessarily. I
7 just wanted to be sure that if there were, we
8 raise them at this point. Sam.

9 MEMBER BIERNER: So let me just
10 ask you if you would like to comment on any
11 aspects of that validity testing and any
12 issues that you're going to bring forth, any
13 other information that you were wanting to
14 consider?

15 DR. PACE: Are you asking about
16 the -- which measures? The three that --

17 MEMBER BIERNER: The three that
18 were under consideration, because we're not
19 talking about the other three.

20 DR. PACE: Okay, all right.

21 MEMBER BIERNER: Or do you want to
22 talk about the three that were not --

1 CO-CHAIR PARTRIDGE: We're not
2 worrying about the three we've deferred.
3 We're focusing solely on the three that are
4 moving forward.

5 CO-CHAIR MERLINO: So the comments
6 about validity were for all six. We didn't
7 break them out in the staff comments, did we?

8 DR. PACE: Right. So and maybe
9 Dawn has something to say about this, but
10 we'll ask the developers to specifically
11 address validity. Because it's hard to
12 discern from this actual validity testing for
13 those three measures. But, Dawn, can you be
14 --

15 MEMBER DOWDING: That was actually
16 what I was going to ask. I wondered if they
17 could talk us through how they've done the
18 validity testing, because I couldn't actually
19 see it. It was just a repeat of the
20 reliability testing, which I think is what's
21 come up in the notes that we got.

22 So, yeah. I understand it's pilot

1 data and it's a pilot instrument, but is there
2 any data on validity?

3 MS. CRAWLEY: You're correct. We
4 did repeat the information that was in the
5 reliability section in the validity section as
6 well, because it was sort of a combination of
7 the analysis that was done from the pilot
8 data.

9 We did bring forth today some
10 information that we could share that looked at
11 the composite scores versus the global
12 ratings, to look at the validity of those
13 scores, which were all significant at the
14 0.001 level. But, again, we did not have it
15 in the packet.

16 MS. GOLDSTEIN: So we could go
17 through these quarterly. There aren't that
18 many numbers. For nephrologist
19 communications, the first --

20 DR. PACE: Before you give us the
21 numbers, could you just give us a little more
22 explanation of what numbers you're going to be

1 giving us? Is it correlation of the --

2 MS. GOLDSTEIN: It's a correlation
3 between the scales or multi-item measures and
4 the three global ratings.

5 DR. PACE: Okay, and is this
6 patient level or performance score level or
7 both?

8 MS. GOLDSTEIN: This is patient
9 level.

10 DR. PACE: Patient level, okay.

11 MEMBER BIERNER: We have a white
12 paper board we could actually write --

13 MS. GOLDSTEIN: Oh, do you want us
14 to do it there?

15 (Pause.)

16 MEMBER DOWDING: Sorry. Can we
17 just clarify? We were just discussing. So to
18 meet the criteria for NQF endorsement we have
19 to have validity data at the organization
20 level as well as individual patient level. Is
21 that right?

22 DR. PACE: Yes, at both levels.

1 MEMBER DOWDING: At both levels.

2 DR. PACE: Now, at the
3 organization level it doesn't always have to
4 be empirical. We do still allow for some face
5 validity.

6 But generally, for the CAHPS
7 measures, they've been kind of doing the same
8 correlation but doing it at the patient level
9 and then also doing it with the computed score
10 level, but I don't know if they've done that
11 in this case.

12 (Pause.)

13 DR. PACE: Liz or Barbara, do you
14 want to explain or just --

15 MS. CRAWLEY: Okay, this was our
16 evidence of construct validity where we looked
17 at the three measures that were made up of
18 multiple items: doctor communication, quality
19 of the center, care and operations and
20 providing information to the patients versus
21 the global ratings of the nephrologist, the
22 staff and the center. And all of these

1 correlations were significant at p less than
2 0.001.

3 DR. PACE: And that's a typical
4 way of looking at validity. So basically the
5 idea is that the scale, you know, it's kind of
6 their hypothesis, that if people are rating
7 doctor communication high, then you would
8 expect the global rating of doctor
9 communication to be in the same direction and,
10 you know, pretty well correlated.

11 It's not the exact same measure
12 so, you know, you're not going to see, like,
13 0.9 or 1, but they should be decent
14 correlations and significant.

15 MEMBER BIERNER: I just wanted to
16 ask, on the third of those, providing
17 information, that's apparently somewhat lower
18 than all the others, what is your
19 interpretation of that and was there anything
20 done as a result of that?

21 MS. CRAWLEY: We probably have
22 dropped some questions that were on the pilot

1 testing because of this finding. Originally,
2 the questionnaire was, let me think, 70
3 questions long.

4 Now we have it down to 58 because
5 we did drop questions because they did not
6 meet a certain standard that was set. So that
7 might explain why it's so low here. It's
8 still significant, statistically significant.

9 MEMBER BEVANS: I guess in
10 response to that, my question would be are we
11 being asked to vote on the pilot test version,
12 for which we have evidence, or the sort of
13 revised version of the instrument at this
14 point? Because we don't have those data,
15 right, like, what these validity or
16 reliability statistics look like for the final
17 scale compositions?

18 MS. CRAWLEY: Not at this time we
19 don't.

20 MS. GOLDSTEIN: We could.

21 MS. CRAWLEY: We could, yeah. We
22 could, yeah.

1 CO-CHAIR MERLINO: You're going to
2 roll out to 5,800 centers? That's the plan?

3 MS. CRAWLEY: That's the plan.

4 CO-CHAIR MERLINO: With the pilot
5 from 32 facilities?

6 MS. CRAWLEY: We have 22 approved
7 vendors who are taking on this task.

8 MS. GOLDSTEIN: I mean, in
9 addition to the pilot we did, we did do a
10 quality improvement project. So a number of
11 facilities used the survey to make
12 improvements in the operations of the
13 facilities, and it was very successful.

14 So many facilities have been
15 using, you know, the survey and have been
16 making, you know, quality improvement actions
17 to improve their care.

18 CO-CHAIR PARTRIDGE: Lisa.

19 MEMBER MORRISSE: I really want to
20 be respectful here and say that I appreciate
21 the effort that has gone into this and feel
22 very strongly about the importance and need of

1 this level of score.

2 But I'm feeling also very much
3 like we're not voting with sufficient
4 information based on what you are suggesting
5 is your current effort, and that perhaps what
6 we need to do is go back to the drawing board
7 and look at this again with a more complete
8 set of data, both for us and for those who are
9 not currently in the room.

10 CO-CHAIR PARTRIDGE: Becky.

11 MEMBER BRADLEY: There were some
12 questions about the definition of the term
13 "respect" on the survey and how you all
14 defined that. And there was some missing data
15 in some of the tables there related to the
16 respect question. Can you clarify that for
17 us?

18 MS. CRAWLEY: I think, if I recall
19 correctly, there was one row that had missing
20 information and I think when I looked back at
21 the data that we had on hand, the tables I had
22 on hand, one of the variables got repeated in

1 the output.

2 And so we just don't have that at
3 this time. Maybe that's one of the other ones
4 we can ask them to provide for us shortly.
5 I'm trying to remember which one it was. Here
6 it is. The "show respect" under quality,
7 that's the one you're referring to?

8 DR. PACE: But I think in general
9 and -- Liz and Barbara, you can correct me if
10 I'm wrong -- but in general when that question
11 is asked about are you treated with respect,
12 it's from each individual's perspective of
13 their idea of respect.

14 So I don't believe we're ever
15 going to see, you know, "and we define respect
16 this way. But correct me if I'm wrong." Is
17 that a fair --

18 MS. CRAWLEY: Yes.

19 MS. GOLDSTEIN: Yes, that is
20 correct. I mean, also these correlations when
21 you're looking at them, providing information
22 is not going to be as correlated to the

1 doctor, the staff, even the center. It's not
2 a direct. It's a little bit different
3 measure.

4 If they were as high as the
5 quality of the center-doctor communication,
6 you know, I'd be extremely surprised, so.

7 DR. PACE: Right, and so it's not
8 just about the significance but the size. And
9 what Liz is saying is that from a conceptual
10 standpoint you would not expect that to be as
11 high as the others.

12 And I think that makes sense and
13 this is at the patient level data but we
14 still, I assume you could do this at the score
15 level as well since you have that data
16 perhaps.

17 CO-CHAIR PARTRIDGE: Sherri.

18 MEMBER LOEB: Just a quick, I
19 mean, no, you can't necessarily define respect
20 because it's different for each person. But
21 you have data in other categories for respect,
22 I mean, you have it under nephrologist

1 communication and caring but you don't have it
2 under the other.

3 And I would tend to agree with
4 Lisa, that I feel like we're trying to approve
5 something where there's just so many holes
6 that we don't have all the information to
7 really make, I mean, an educated, fair
8 decision.

9 DR. PACE: Okay, so what we'll do
10 is vote on validity and we're talking about
11 the three measures that you approved under
12 reliability and your options will be high,
13 moderate, low, or if you feel there's
14 insufficient information that's what you would
15 vote here. Does that make sense?

16 MS. ALLEN: So we'll start the
17 voting on validity. Results for validity, two
18 high, five moderate, three low, seven
19 insufficient.

20 (Off microphone comments)

21 DR. PACE: Okay, we're trying to
22 compute here. In order for it to move --

1 Okay, if the high and moderate is in the 40 to
2 60 percent range, we consider that the gray
3 zone and we will continue looking at the rest
4 of the criteria.

5 And then you'll vote on, well, so
6 we'll continue to move through and look at
7 feasibility and usability for the three
8 measures unless anyone wants to make any
9 comment about this vote because it's quite a
10 range from high, meaning there was testing at
11 both levels, to insufficient information, so.

12 CO-CHAIR PARTRIDGE: I think Liz
13 has dropped off the phone.

14 MS. DORIAN: Yes, I'm just
15 checking with her. She wasn't there.

16 DR. PACE: Okay, let's re-vote
17 because Liz has joined us back. So let's go
18 ahead and do re-vote on validity, and I
19 apologize that we didn't get that in, so.

20 MS. ALLEN: So now we're voting on
21 validity, one high, two moderate, three low,
22 four insufficient. Voting starts now. And

1 the results are in, two high, six moderate,
2 two low, eight insufficient.

3 DR. PACE: Okay, still in the gray
4 zone. Still the gray zone so we'll continue
5 through the rest of the criteria for these
6 three measures. Okay, so next is feasibility.
7 And for those of you who reviewed that or any
8 committee members, any comments?

9 MEMBER BIERNER: I wanted to ask a
10 question. Given, I know this is being done by
11 vendors. Approximately how long does it take
12 to administer? Do you have any feel for that?

13 MS. CRAWLEY: We have no idea of
14 how long it takes to do it by mail of course.
15 By telephone we are thinking it's an average
16 of about 15 minutes.

17 MEMBER BIERNER: Fifty?

18 MS. GOLDSTEIN: Fifteen.

19 MS. CRAWLEY: Fifteen, 1-5, 15.

20 Well, there are some skip questions. If you,
21 you know, answer some yes or no, then you
22 might skip a block of questions.

1 (Off microphone comments)

2 MS. CRAWLEY: We have shortened
3 the telephone script for the intro for the
4 national implementation. I would have to go
5 back and look at what the telephone script
6 looked like.

7 It was much longer because for the
8 national implementation we, you know, we kept
9 it with few modifications. But, you know, we
10 have shortened it for the national
11 implementation. So, yes, there is an intro in
12 the telephone script.

13 And in the mail version you get a
14 pre-notification letter and then you get a
15 mail cover letter letting you know the
16 background and why we encourage you to
17 participate.

18 MEMBER THOMAS: In terms of the
19 feasibility and usability, it strikes me that
20 this is going to be implemented nationwide,
21 you know, this year, next year. It strikes me
22 that it would be really high, that feasibility

1 would be.

2 FEMALE PARTICIPANT: The question
3 is moot.

4 MEMBER THOMAS: Right. I mean,
5 it's going to be in every dialysis clinic
6 across the country soon, right?

7 DR. PACE: Right, but that doesn't
8 -- Yes, I mean, the question is how feasible
9 you think it is or what the burden's going to
10 be to both patients and facilities, but you're
11 right the --

12 MEMBER THOMAS: They'll then be
13 tying it to payment and eventually, it's just
14 reporting first and then payment eventually.
15 So not participating is going to be a
16 financial penalty so I would suggest that this
17 is a pretty high feasibility and usability
18 score.

19 MEMBER BRADLEY: I guess my
20 question sort of relates to that in that
21 earlier in the information it said there were
22 no licensing fees or anything.

1 But there will be vendor fees
2 associated with this that will be somewhat of
3 an added burden to hospitals that are not
4 currently collecting this data. Is that
5 correct?

6 MS. CRAWLEY: Each dialysis
7 facility will have to hire a third-party
8 vendor to participate so, yes, there will be
9 those fees that they will have to carry.

10 CO-CHAIR MERLINO: Any other
11 questions or comments? We're voting on
12 feasibility.

13 MS. ALLEN: We're voting on
14 feasibility, one high, two moderate, three
15 low, four insufficient. Voting starts now.
16 The results are in, seven high, ten moderate,
17 one low, zero insufficient.

18 DR. PACE: Okay, let's move on to
19 usability and use.

20 CO-CHAIR MERLINO: Comments?
21 Questions?

22 DR. PACE: Everybody knows it's

1 planned for use, so.

2 CO-CHAIR MERLINO: Anything?

3 Should we just move to a vote? Peter, do you
4 have a question? No. All right, we're ready
5 to vote. You want to move on, don't you? All
6 right, usability and use, we're voting.

7 MS. ALLEN: All right, beginning
8 the vote on usability and use, one high, two
9 moderate, three low, and four insufficient
10 information. Starting now. All the votes are
11 in, nine high, five moderate, two low, and two
12 insufficient information.

13 DR. PACE: Okay, let's move on to
14 the overall suitability for endorsement. And
15 we're talking about the three performance
16 measures based on the multi-item scales in the
17 in-center dialysis survey. Okay.

18 MS. ALLEN: We're voting on the
19 overall suitability for endorsement for
20 Measure 0258 and we're only voting on those
21 three measures identified, one yes, two no.
22 Voting starts now. All votes are in. Ten

1 yes, eight no.

2 DR. PACE: Okay, it remains in the
3 gray zone and probably they'll have some
4 additional information for us on the
5 performance measure level so I think we'll be
6 able to get that cleared up and we will work
7 with them to get the information during the
8 comment period, so thank you.

9 MS. DORIAN: Thank you. So we'll
10 move on to our next measure which is 0517, the
11 CAHPS Home Health Care Survey. And, Liz, I
12 believe you're staying up here and I'm not
13 sure who else.

14 MS. GOLDSTEIN: I'm staying here
15 and Lori Teichman is on the phone also for
16 this one.

17 MS. DORIAN: Hi, Lori. Are you
18 there?

19 MS. TEICHMAN: Hi.

20 MS. DORIAN: Hi.

21 MS. TEICHMAN: Thank you.

22 MS. GOLDSTEIN: Okay, so I'm going

1 to give you some background on the survey.
2 This is our Home Health Care CAHPS Survey.
3 This was initially NQF endorsed in March 2009.
4 This survey is required for our Medicare-
5 certified home health agencies and they've
6 been collecting it for a couple years.

7 For this survey, again, we have
8 very detailed protocols. So this is our
9 manual, pretty thick.

10 There are approximately 9,000 home
11 health agencies so the results when we present
12 reliability and other information, it's about
13 1.4 million surveys.

14 I just want to make one point
15 about the home health industry. There is lots
16 of flux in this industry with agencies coming
17 and going.

18 So, for example, for looking at
19 improvements over time, we've seen a little
20 movement, not great movement yet, but we think
21 part of this is because we have a number of
22 agencies that close each year and a number of

1 agencies that come in.

2 Out of any of our surveys that
3 we've nationally implemented, I think this is
4 the one where we see the most changes in terms
5 of the providers included in the survey.

6 Just to make a couple more points.
7 I think this survey is unique in that 61
8 percent of patients responding to the survey
9 are 75 years or older and almost 30 percent
10 are over 85 years old.

11 So it's definitely an older
12 population than some of our other surveys.
13 It, again, is a very vulnerable population
14 also with, you know, home health workers
15 coming into people's homes.

16 For this survey, we do have
17 translations in Spanish, Russian, Chinese,
18 both simplified and traditional, and
19 Vietnamese.

20 Just a couple more points to
21 emphasize is that there are five measures, so
22 there are three measures that are multi-item

1 and then two global ratings.

2 And I guess the other point to
3 emphasize, and maybe it's when we get to that
4 section, we have done some analysis of
5 disparities and so I could maybe, I'll hold
6 that information until we get to that section
7 because we do see some disparities in care in
8 terms of this survey. So I think I'll stop
9 there.

10 I guess another point, and I'm not
11 sure if some of our attachments weren't
12 attached or not because from some of the
13 questions we got from NQF in the Excel file it
14 seemed like all the information that was
15 provided wasn't being seen so I don't know if
16 there was an issue there.

17 So I'll try, if there are gaps or
18 something, I'll try to fill that in but we may
19 need to have a discussion afterwards and make
20 sure, did you get all the various attachments
21 because some of the stuff we were surprised,
22 that it's right there so, yes, we're not sure.

1 DR. PACE: Okay, well, and
2 definitely point out something that you think
3 is there and --

4 MS. GOLDSTEIN: And may not be
5 there or something.

6 DR. PACE: Well, and it may be.
7 We may have missed it.

8 MS. GOLDSTEIN: Okay, okay.

9 CO-CHAIR MERLINO: Any comments?
10 Questions? Evidence. Who reviewed it?
11 Anybody want to kick it off from the phone?

12 MEMBER BIERNER: I mean, I think
13 there's fairly strong evidence of the need for
14 it. It's very widespread, you know, form of
15 health care. It's nationwide.

16 MEMBER MORRISSE: We utilized home
17 health care in home every night for over ten
18 years and that was pediatric so it would be
19 excluded from the survey.

20 And I would suggest that
21 eventually pediatric should be included
22 because amongst my group, and I help

1 facilitate a family group of over 1,000
2 families in my state, many of whom utilize
3 home health care on a regular basis, they
4 scream all the time about their agencies and
5 whether they are doing a good job or not.

6 But we have also had a recent
7 encounter as an adult and as I was reading
8 through this I have to say that one of the
9 drums that I beat regularly is that medical
10 reconciliation is more than going over a list
11 of meds.

12 And I was so excited to see the
13 questions around your prescription medications
14 going in more depth because they did not with
15 us.

16 CO-CHAIR MERLINO: Liz, any
17 comment on including peds at some point?

18 MS. GOLDSTEIN: We get that
19 question a lot for a lot of our surveys. Most
20 of our surveys focus, that at least my group
21 works on, on the Medicare population so there
22 aren't too many, you know, pediatric patients

1 that are Medicare eligible.

2 That said, I think for some of our
3 surveys we are starting to have some
4 discussions about that.

5 CO-CHAIR MERLINO: Esther. Dawn,
6 sorry.

7 MEMBER DOWDING: It's okay. Yes,
8 I just wanted to say coming from a home health
9 care agency I think that this is actually a
10 measure that's used and it's a measure that
11 informs quality improvement programs. So I
12 would strongly support the use of it in terms
13 of the evidence base for it.

14 CO-CHAIR MERLINO: Chris.

15 FEMALE PARTICIPANT: And you can
16 probably speak directly to the actions that --

17 MEMBER DOWDING: Oh, yes. Oh,
18 yes. We take the HCAHPS Home Care Patient
19 Satisfaction Survey very seriously and it is
20 informing quality improvement programs in our
21 agency because of the measures that are coming
22 out. So I would say there's very strong

1 evidence for it.

2 CO-CHAIR MERLINO: Chris, and then
3 we'll go to --

4 MEMBER STILLE: Yes, I just wanted
5 to echo Lisa's concern. You know, for a lot
6 of the measures there's a reasonable rationale
7 for excluding children from this but I would
8 think that the perceptions of parents are
9 pretty much the same as the perceptions of any
10 other caregivers or of other patients, so I
11 really have trouble with the exclusion of
12 children in this.

13 CO-CHAIR MERLINO: Sherri, then
14 Lisa.

15 MEMBER LOEB: Taking off my NQF
16 hat and my nurse's hat, from a spouse hat the
17 home care that we received and the medication
18 reconciliation and review of the whole person
19 was by far so exceeded any care we got from
20 any other caregiver that it's truly is a
21 phenomenal thing and I can't speak highly
22 enough and I know all home health agencies

1 don't benefit that but the home health nurse
2 that we had, he truly made a difference in his
3 care so kudos.

4 CO-CHAIR MERLINO: Lisa.

5 MEMBER MORRISE: Yes, the nurses
6 can make and other staff that come from home
7 health can make a huge difference in keeping
8 a patient out of the hospital, which was
9 certainly our case and why we were a part of
10 an approved Medicaid waiver.

11 And, in fact, most of the
12 children, I don't know if this is true in
13 Colorado, Chris, but most of the children who
14 are able to access home care indeed are
15 Medicaid patients so I think it would be
16 something that CMS would be very interested
17 in, to look at the pediatric population.

18 And many of those individuals who
19 are receiving service are receiving service
20 from agencies that don't have a pediatric-
21 specific arm but are just home health agencies
22 with a major adult provider cohort as well.

1 CO-CHAIR MERLINO: Chris, any --

2 MEMBER STILLE: Right. No, your
3 speculation is right. You know, most kids who
4 would get home health care are receiving SSI
5 and Medicaid and so this is a tremendously
6 important thing to government payers.

7 CO-CHAIR MERLINO: Anybody want to
8 speak negatively? Why don't we vote on this
9 and then we can move to the next one.

10 DR. PACE: So we're talking about
11 evidence, that there's rationale that supports
12 that there are health care interventions that
13 can influence the home health experience being
14 measured. Okay.

15 MS. ALLEN: We're voting on
16 evidence, one yes, two no. Voting starts now.
17 All votes are in. Results 18 yes, zero no.

18 CO-CHAIR MERLINO: Okay, we'll
19 move on to performance gap.

20 DR. PACE: Okay, Liz, I think you
21 had some information here. I think there was
22 mention that it was in the measure testing

1 attachment and I didn't see it there but --

2 MS. GOLDSTEIN: So I think in
3 terms of the performance gap --

4 CO-CHAIR MERLINO: Mic.

5 MS. GOLDSTEIN: Okay, in terms of
6 the performance gap, we have in the form
7 information about what scores, you know, look
8 like today.

9 But to add to that, we have looked
10 at disparities in terms of these measures.
11 And what we're seeing in particular for the
12 care of patients and the communication between
13 providers and patients, we are seeing within
14 agency effect.

15 So minorities for these two
16 measures are reporting lower scores than
17 whites. You know, it's not by a huge amount
18 but there are, you know, differences and these
19 are, we're seeing it really within agencies.
20 When we go across agencies versus within,
21 that's where we're seeing it.

22 So there is clearly, I mean,

1 general scores are fairly high for all of our
2 different measures but there is variation
3 among the different agencies around the
4 country.

5 CO-CHAIR MERLINO: Comments?

6 Lisa.

7 MEMBER MORRISE: So my question to
8 that specifically would be is there a
9 correlation in, so do you look at
10 socioeconomic, although I probably should have
11 drilled down into this information, but is it
12 a socioeconomic situation or a ethnic
13 disparity situation?

14 I say that because the parents
15 most likely to complain about being treated
16 poorly are those who have the lower education
17 levels and the lower economic level.

18 MS. GOLDSTEIN: Right. When we're
19 looking at race, ethnicity, we're controlling
20 for the education. And education is our, you
21 know, measure that we have of socioeconomic
22 status. So even controlling for, you know,

1 education you're seeing some of these
2 differences.

3 DR. PACE: And just to clarify,
4 Liz, I think the details about ethnicity and
5 race were put into the data dictionary, lots
6 of tables. And so we were just kind of
7 looking for some summary, but that part was in
8 the data dictionary so that was there.

9 MEMBER THOMAS: But a fair amount
10 wasn't there, right? I mean, I'm looking at
11 some of the staff notes that note that there's
12 no information on the performance provided, no
13 information on the agency performance
14 provided, disparities we just mentioned, no
15 summary of the performance based on
16 performance measures and recommended that this
17 might be considered insufficient. So is some
18 of that covered in the documents that you've
19 said you've submitted that --

20 MS. GOLDSTEIN: Yes, so the scores
21 are included in the documents we submitted.

22 DR. PACE: So can you tell us

1 where?

2 MS. GOLDSTEIN: So it's in --

3 (Off microphone comments)

4 MS. GOLDSTEIN: Yes, measured
5 testing form.

6 DR. PACE: So we'll pull that up.

7 MS. GOLDSTEIN: Is the measure
8 patient mix adjusted? Yes, it is. So for --

9 (Off microphone comments)

10 DR. PACE: So are you opening the
11 measure testing form so we can see that? So
12 go to 2A. Find 2A and then click on the
13 measure testing. There we go.

14 Okay, so we have the demographic
15 characteristics in a table, patient mix
16 adjustment factors, factor loading, item total
17 correlations and missing data but --

18 MS. GOLDSTEIN: There should be a
19 Table 8.

20 DR. PACE: Okay, Table 8. Thank
21 you. Keep going. There we go. All right.
22 So, Liz, you want to just kind of walk us

1 through this? Thanks.

2 MS. GOLDSTEIN: So this is, gives
3 the average median, mode, all the information,
4 standard deviation. These are, you know,
5 agencies that have more than ten completes on
6 the survey. So it's about 8,000 agencies for
7 our five measures.

8 DR. PACE: And just to explain,
9 the interquartile range is between the 25th
10 percentile of scores and of agency scores in
11 the 75th percentile.

12 So that means, for example, on
13 care of patients there's a six-point
14 difference between agency scores at the 25th
15 versus the 75th percentile.

16 Okay. So that's the agency
17 performance on these measures as specified.
18 Okay, so it shows some variability. And any
19 more questions about that or, Lee.

20 CO-CHAIR PARTRIDGE: Can we go
21 back a couple of minutes in which we were
22 talking about case mix or patient mix

1 adjustment?

2 In these numbers that we're
3 looking at, Liz, have you made some
4 adjustments based on the data that you had in
5 the preceding page, that is education or --

6 MS. GOLDSTEIN: Yes, so for the
7 CAHPS surveys, we always do patient mix.
8 There's been analyses for years and years that
9 certain patient characteristics influence how
10 patients respond to patient experience of
11 survey.

12 So any data that CMS uses, we do
13 adjust for patient mix. Otherwise, you know,
14 we clearly wouldn't be doing apples to apples
15 comparison. So, again, you know, that is part
16 of our protocols so --

17 CO-CHAIR PARTRIDGE: But suppose I
18 wanted to know the extent to which this number
19 has been adjusted based on whether or not the
20 population responding is over 75 or completed
21 less than a high school education or so on.

22 How would I know what the

1 unadjusted number would have been and do --
2 I'm just trying to get, I know this matters in
3 some other CAHPS surveys and I'm not sure it
4 matters quite as much here but I think we're
5 going to end up spending some time on it
6 probably later today or tomorrow.

7 To the purchaser or did the
8 consumer or did the provider, they don't know
9 how much that number has been adjusted by
10 those demographics, right?

11 MS. GOLDSTEIN: So the providers
12 do know because we always give the models back
13 to them and some of our providers -- I do a
14 lot of stuff on health plans. Those providers
15 know those adjustments by, you know, the exact
16 amount.

17 CO-CHAIR PARTRIDGE: Yes, I know.

18 MS. GOLDSTEIN: They have them
19 memorized. So providers do know. We make
20 that information available to them.

21 The consumer doesn't know that,
22 you know, they don't get when they're

1 reviewing the website into that detail that
2 the data is adjusted.

3 But it does ensure, for example,
4 an agency that may be serving, you know, a
5 very different population than your average
6 population, they could, if we don't adjust,
7 they could be hurt by that if they do have a
8 different, you know, group that gives lower
9 responses.

10 DR. PACE: And let me just clarify
11 that, you know, the NQF criteria do not, I
12 mean, we are endorsing the performance score
13 and, you know, if adjustment is necessary and
14 justified in the analysis it should be done.

15 So we don't require additional
16 reporting so it is something that, it's not
17 evident from an adjusted score. You're right.

18 MS. TEICHMAN: I'm sorry to
19 interrupt. This is Lori and I just wanted to
20 let you know that we, you know, we post the
21 data quarterly on Medicare.gov on Home Health
22 Compare and every quarter the patient mix is

1 recalculated and we post all of the updates to
2 the patient mix adjustments.

3 And what we do on Home Health
4 Compare is that there's a link so if somebody
5 does want to see what the adjustment scores
6 are, there's a link right to the
7 homehealthcahps.org website and there's a
8 whole table that shows the adjusted factors
9 for the data that was just put up and also,
10 like, a two-page explanation of what it all
11 means.

12 CO-CHAIR PARTRIDGE: But if I'm
13 trying to figure out whether this home health
14 agency is likely to provide very good care to
15 my grandmother who has only an eighth-grade
16 education, what I'm struggling with is I don't
17 know to what extent these numbers are masking-
18 - information would be useful to me.

19 DR. PACE: Right, right. So let
20 me just say in general I think, as Liz was
21 saying, the purpose of these are comparative
22 performance assessment.

1 So the question is, you know, if
2 you're going to do a list and you want to ask
3 the question how would these agencies compare
4 if they were taking care of the same mix of
5 patients, that's the purpose for adjustment.

6 And so that's all we're asking for
7 at this point, but it's the central question
8 to adjusting for sociodemographic status
9 factors that --

10 CO-CHAIR PARTRIDGE: And as Karen
11 knows, those of us on CSAC have spent four
12 months on that issue so it's very relevant in
13 our minds.

14 DR. PACE: Okay, so this is the
15 distribution of the performance score as it's
16 computed with adjustment, and are people ready
17 to vote on performance gap?

18 MS. ALLEN: So we're starting the
19 vote on performance gap, one high, two
20 moderate, three low, four insufficient.
21 Starting the votes now. All votes are in, 12
22 high, six moderate, zero low, zero

1 insufficient.

2 DR. PACE: Okay. Let's move on to
3 high priority and any discussion here?
4 Everybody ready to vote? Let's move on. High
5 priority.

6 MS. ALLEN: We're starting the
7 vote on high priority, one high, two moderate,
8 three low, four insufficient. Starting the
9 votes now. All votes are in, 18 high, zero
10 moderate, zero low, zero insufficient.

11 DR. PACE: Okay, so let's move on
12 to reliability and, again, this would include
13 the specifications including the case mix
14 adjustment and exclusions, et cetera, as well
15 as the reliability testing which we expect at
16 both the patient level instrument and scales
17 as well as the computed performance measures.

18 And remember, we're looking at
19 five measures so if there are any questions
20 about individual measures to note that and
21 I'll stop there and see what the reviewers --

22 CO-CHAIR MERLINO: Anybody?

1 Peter.

2 MEMBER BIERNER: Oh, I thought it
3 was strong.

4 CO-CHAIR MERLINO: Peter.

5 MEMBER THOMAS: So I just want to
6 confirm that 1.5 million patients were
7 surveyed in all states? Is that correct?

8 MS. GOLDSTEIN: Correct.

9 MS. TEICHMAN: Yes.

10 MEMBER THOMAS: That's 10,000 home
11 health agencies annually will --

12 MS. GOLDSTEIN: This includes
13 about 8,000 home health agencies, the
14 analysis.

15 MEMBER THOMAS: Any reason why,
16 that you can tell, anything relevant about why
17 63 percent of the survey takers were women and
18 37 male? Is that just the demographics?

19 MS. GOLDSTEIN: I think it's the
20 demographics of who's using home health.

21 MEMBER THOMAS: Yes. So the
22 algorithm rated this as high? You could rate

1 it as high, right, 0.7 percent for all
2 performance --

3 DR. PACE: Eligible. If you had
4 concerns, you could rate it moderate but it
5 was testing at both levels and the data were
6 good. We could bring this up in the measure
7 testing form. I think they have a couple --
8 It's a little lost in here where we have the
9 --

10 MEMBER THOMAS: But for all
11 performance measures it was --

12 DR. PACE: Oh, right. I'm sorry.

13 MEMBER THOMAS: -- over 0.7?

14 DR. PACE: There it is.

15 MEMBER THOMAS: 0.7, right,
16 Cronbach's alpha?

17 DR. PACE: Right. The Cronbach's
18 alphas are for the three multi-item scales.
19 We don't have the patient level data for the
20 global items but they do have the performance
21 measure level information for all five which
22 you'll see there, .85, .80, .84, .79 and .77.

1 So those were all above .70. Okay. Any other
2 comments? Okay, ready to vote, reliability
3 for all five.

4 MS. ALLEN: We're voting on
5 reliability, one high, two moderate, three
6 low, four insufficient. Starting the votes
7 now. All votes are in. The results show 14
8 high, four moderate, zero low, zero
9 insufficient.

10 DR. PACE: Validity, so any
11 thoughts about validity testing? Peter.

12 MEMBER THOMAS: Please, go ahead.

13 MEMBER LEVINE: I raised this in
14 the work group call. I'm just a little
15 concerned about the standard for inclusion,
16 that you only had to have one home care visit
17 in two months.

18 It seemed very modest on which to
19 base a judgment as a patient on the home care
20 agency compared to, say, we didn't talk about
21 this but the dialysis center which said you
22 had to have three months of practically daily

1 experience. So I just wondered how that got
2 decided.

3 MS. GOLDSTEIN: So, it's --

4 MS. TEICHMAN: Hi, this is -- Oh,
5 I'm sorry.

6 MS. GOLDSTEIN: Oh, that's okay,
7 Lori. I was just going to say it's two
8 skilled visits over that two-month period, so
9 one during the sample month and at least one,
10 you know, during the sample month or the prior
11 month.

12 There are a lot of home health
13 care patients, we'd be excluding a sizable
14 number, that receive maybe an IV or something
15 only once a month.

16 So we would be -- And a lot of
17 these patients receive home health care for
18 months and months and months or years maybe.
19 So we would be excluding, I can't say the
20 exact percentage but a significant number of
21 patients from our evaluations.

22 So that's why when the survey was

1 developed we did not want to, you know,
2 exclude this group. They were having enough
3 experience with the agency in particular since
4 a lot of these patients are receiving it for
5 extended periods of time.

6 MEMBER LEVINE: I just think for
7 all of those submissions, I think it would
8 really be helpful if that kind of question got
9 anticipated and explained so that we would
10 know why certain choices were made because the
11 questions will always come up.

12 MEMBER THOMAS: I can't --

13 FEMALE PARTICIPANT: Oh, I think
14 the phone cut out. No.

15 MEMBER THOMAS: Some of the notes
16 in the staff notes and then I corroborated it
17 with my own review and I tried to figure out
18 what I thought independently of it and it just
19 strikes me that there are some real questions
20 about whether there is sufficient validity
21 testing here.

22 So I'm just trying to get a better

1 sense for, for instance, some of the notes
2 that I was provided with by staff suggested
3 that some of the things that were being put
4 forward as valid to assess validity actually
5 weren't really on target. So can someone
6 explain kind of that perspective because I'm
7 not hearing that come out in our discussion?

8 DR. PACE: So, Liz, what was
9 presented was item to total correlations and
10 IRT parameters for the home health care CAHPS
11 and generally, a lot of times, the item to
12 total correlations are used as part of the
13 reliability versus validity.

14 We did find the validity testing
15 in Table, for the measure score, I believe in
16 Table 9, the correlations there. But maybe
17 you want to speak to the item to total
18 correlation.

19 MS. GOLDSTEIN: I guess it would
20 be helpful to know what other types of things
21 you'd be looking under validity for. I mean,
22 we have data so we can clearly run anything.

1 DR. PACE: Right. Well, I think
2 what you were presenting before, you were
3 looking at the correlation of the composite to
4 the global rating.

5 MS. GOLDSTEIN: Which we did.

6 DR. PACE: This is the performance
7 measure level, right? These are the
8 performance measure -- Yes. So this would be
9 what we are looking for for the performance
10 measure. Exactly.

11 So the question is were you
12 presenting the, let's see, you had a table of
13 factor loadings and then you had a Table 4 of
14 item total correlations. What were you
15 presenting --

16 MS. GOLDSTEIN: I mean, I think
17 all of it was presented to look at different
18 aspects of validity.

19 So, I mean, the item total
20 correlations, we're making sure that the
21 individual items were correlated, you know,
22 within their composite and not to items in

1 other composite.

2 So I think we tried to look at it
3 different ways. I think on the form it's not
4 completely clear. It wasn't at least clear to
5 us, you know, exactly what you're looking for
6 for validity.

7 DR. PACE: Right. I think for
8 some of the CAHPS though measures you've been
9 submitting the, or maybe other CAHPS, but what
10 you showed for the previous one, where you
11 were looking at more the computed composite
12 score correlated to a global rating --

13 MS. GOLDSTEIN: Yes, well, that's
14 there too. It's here also.

15 DR. PACE: So, okay.

16 MS. GOLDSTEIN: That was Table 9.

17 DR. PACE: Well, that was at the
18 performance score level, right?

19 MS. GOLDSTEIN: Yes.

20 DR. PACE: Okay, so in some of the
21 submissions that's been done at both levels,
22 right?

1 MS. GOLDSTEIN: Yes.

2 DR. PACE: Okay. So if you could
3 just, you know, I guess tell the committee how
4 you looked at validity of the patient level
5 scales, then they can go ahead and vote.

6 Dawn, Len, any comments about --

7 MEMBER DOWDING: No, I mean, I
8 didn't have any concerns about this measure
9 but that's probably because I'm very familiar
10 with it, so.

11 MEMBER BIERNER: Well, I mean, in
12 the Table 8 they give some agency-level
13 descriptive statistics that show certainly a
14 range of responses, some of them very low if
15 you look over the minimal and max portions of
16 the table. So I don't have concerns with it
17 in terms of validity.

18 DR. PACE: Right, and that's
19 really about the performance spread but that's
20 good. So I'll just ask if you want to make
21 any comment about the -- Okay.

22 So basically if you look at the

1 item, the total correlations in Table 4, this
2 is about now individual questions, how it
3 relates to the composite.

4 So it's a little bit different
5 than what we were looking at before and with
6 some other measures where they actually took
7 the composite and correlated it with some
8 other measure and looked at how they thought
9 that performed.

10 So this is kind of a deeper level
11 that's often used in constructing the scales
12 in terms of looking for consistency of the
13 item to the scale. So we can --

14 CO-CHAIR PARTRIDGE: The question
15 before us is those of --

16 MS. TEICHMAN: This is Lori. I
17 guess I'm at a disadvantage because I'm not in
18 the room and I apologize.

19 I'll be willing to do whatever it
20 takes so I guess specifically I'd like to know
21 what statistic should be run on what for it to
22 get the answers about the patient-level

1 validity? What would you like to see?

2 DR. PACE: So we just wanted you
3 to explain how what you provided is a, how you
4 see that as validity of the scale and we'll
5 have the committee vote on it. And if there's
6 anything else that's needed, we can work with
7 you offline on that but --

8 MS. TEICHMAN: Okay, fine. That
9 sounds great.

10 MEMBER LEVINE: Okay. One more.
11 This is an aside but it's getting a little
12 late and I'm getting a little tired.

13 In reading the questions and I
14 really appreciate when I could just actually
15 see the questions as opposed to we cover five
16 areas and I don't know what they're saying.
17 You know, I was surprised by what's not there.

18 In my fairly extensive experience
19 with families and patients, mostly Medicare
20 but some Medicaid, almost all elderly, there's
21 nothing in here about how long am I going to
22 get this service because so much of Medicare

1 is very time limited.

2 Yes, there are ways of getting an
3 injection, you know, once every week or month
4 or something but most people don't get that,
5 and that's the question they want to know and
6 very frequently the agency doesn't tell them
7 that till the last day and we've documented
8 that.

9 And the other thing is am I going
10 to have to pay for any of this? Nothing about
11 money. You know, all this equipment, is that
12 going to come? What do I have to pay for?
13 That's what people want to know about and
14 that's what, you know, seems to me is missing
15 from this survey.

16 MEMBER DOWDING: There is one
17 question on here about level of service,
18 Question 2. "When you first started getting
19 home health care from this agency, did someone
20 from the agency tell you what care and
21 services you would get?"

22 So we expect them to go through

1 how many visits and that's actually what it's
2 expected to be. Oh, and actually that's what
3 this question picks up, is that it doesn't
4 happen. Yes.

5 DR. PACE: Microphone, please.
6 Would you use your microphone please, Carol?

7 MEMBER LEVINE: It doesn't include
8 duration. As an ordinary person hearing that
9 question, I don't care what, you know, you may
10 intend it to say that but it doesn't say it.

11 MEMBER DOWDING: Sometimes we
12 don't know.

13 DR. PACE: Well, I think Carol has
14 a good point around duration but I think that
15 question does address the gist of what we're
16 getting at.

17 And in terms of payment, I don't
18 think any of the HCAHPS get to how are you
19 going to pay for this? You know, medical
20 finance is probably one of the very top
21 concerns that patients have but I haven't seen
22 it in the other CAHPS measures either.

1 So certainly a legitimate concern
2 and maybe something we can look at addressing
3 down the road.

4 MS. GOLDSTEIN: I know patients
5 are very concerned about what they have to
6 pay, but when you go and talk to patients for
7 all of these surveys it's not something when
8 you ask them, you know, how do you define
9 quality of a home health agency or an ICH
10 facility or a hospital, it's not something
11 that comes to the top of their mind.

12 So I don't think money actually,
13 in all the focus groups I've seen over
14 probably the last ten years in developing
15 these surveys, it's not usually something that
16 they say, you know, defining, you know,
17 quality in a facility.

18 And we're really trying to get at
19 information, you know, from the patient
20 perspective. Is this agency providing, you
21 know, good care? Putting aside, clearly there
22 are money issues across, you know, all

1 agencies.

2 MEMBER MORRISE: So I think that's
3 maybe something that needs to be addressed
4 specifically because it's definitely one of
5 the top concerns that's being mentioned by
6 patient advocates.

7 DR. PACE: And I'll just mention
8 that NQF has had some work on affordability
9 and have had a group of, that has a lot of
10 consumers and patient representatives talking
11 about measures related to affordability.

12 And I think, you know, the
13 question is, you know, I think to actually
14 look at how to develop performance measures in
15 that way versus in a experience with care
16 survey all you could get at is were you
17 informed about different things. And I think
18 they're looking even further than that, are
19 there specific measures about affordability.

20 MEMBER PARISI: Just want to add
21 for those that are not very familiar with the
22 home care operations, to give you a comfort

1 level, a lot of these things that you're
2 raising are addressed throughout the
3 regulatory requirements.

4 And it's probably one of the most
5 heavily regulated industries, is the home
6 health environment, so as it relates to
7 payment and educating the patients and the
8 consumers and the family members about payment
9 sources and required documents that are given,
10 it's very prescribed.

11 So the CAHPS survey isn't designed
12 to look at that. It's more about the
13 perceptions of care so some of those questions
14 as you're evaluating the responses you may
15 drill down to see what information may or may
16 not have been lacking but it should be
17 addressed in the home health environment.

18 MEMBER DOWDING: Yes, can I just
19 echo that? We actually ask our patients if
20 the nurses explained to them how the care will
21 be paid for so it's part of our own internal
22 patient satisfaction survey. So most home

1 health care agencies collect that information.

2 It's just not reported in the HCAHPS.

3 CO-CHAIR MERLINO: Any other
4 questions, comments? So let's vote.

5 MS. ALLEN: So we're voting on
6 validity, one high, two moderate, three low,
7 four insufficient. Starting the vote now.
8 All votes are in. Results show 11 high, six
9 moderate, one low, four insufficient, zero,
10 sorry, zero insufficient.

11 DR. PACE: All right, let's move
12 on. Any comments?

13 CO-CHAIR MERLINO: Let's vote.

14 MS. ALLEN: We're voting on
15 feasibility, one high, two moderate, three
16 low, four insufficient. Voting starts now.
17 All votes are in. Results show 17 high, one
18 moderate, zero low, zero insufficient.

19 DR. PACE: Okay, usability and
20 use. So these are currently publicly
21 reported, right, Liz?

22 MALE PARTICIPANT: Yes.

1 DR. PACE: Yes. Right.

2 MS. GOLDSTEIN: They are publicly
3 reported.

4 DR. PACE: Okay.

5 CO-CHAIR MERLINO: Any questions,
6 comments? Let's vote.

7 MS. ALLEN: We're starting the
8 vote on usability and use, one high, two
9 moderate, three low, four insufficient
10 information. Starting the vote now. All
11 votes are in. Results show 17 high, one
12 moderate, zero low, zero insufficient
13 information.

14 DR. PACE: Okay, overall
15 suitability for endorsement.

16 MS. ALLEN: Now we're voting on
17 overall suitability for endorsement for
18 Measure 0517 CAHPS Home Health Care Survey,
19 one yes, two no. Voting starts now. Please
20 vote again. We're still missing two votes.
21 Please vote again.

22 MALE PARTICIPANT: Everybody check

1 their green lights. There you go.

2 MS. ALLEN: Thank you. All votes
3 are in, 18 yes, zero no.

4 CO-CHAIR MERLINO: So we're going
5 to take a 15-minute break. We're a little
6 ahead of schedule actually so that's good.

7 DR. PACE: Right, so let's --

8 CO-CHAIR PARTRIDGE: Oh, I'm
9 sorry. And I think in a way we've saved the
10 best for last because one of the` measures
11 we're going to be discussing involves a new
12 measure, a new-ish measure, CTM measure and
13 how it's going to mesh with HCAHPS and I think
14 this is actually going to be kind of a fun
15 discussion. And Eric Coleman will be calling
16 in from Colorado, yes.

17 DR. PACE: So let's reconvene at
18 3:20. Thank you.

19 (Whereupon, the above-entitled
20 matter went off the record at 3:02 p.m. and
21 resumed at 3:20 p.m.)

22 MS. DORIAN: Okay, everyone. Just

1 wanted to call your attention to the slide.
2 If you were interested in dinner, we do still
3 have a block of reservations. And I have the
4 name and the location of the restaurant on
5 this slide, so if you wanted to make a note of
6 that.

7 A few people stopped over to let
8 me know, so you still have time. You can send
9 me an email or just stop by.

10 (Off microphone comments)

11 MS. DORIAN: Mio, yes. It's under
12 my name. That's a good point. Or you could
13 say NQF, National Quality Forum. We're there
14 often.

15 So shall we move on to the next
16 measure which is 0166: HCAHPS. And we have --
17 oh, Bill, you're here, great. You want to
18 give an introduction to the measure?

19 MR. LEHRMAN: Thank you. Hello,
20 I'm William Lehrman. I'm the government task
21 leader for the HCAHPS Survey at CMS. And I'd
22 like to give a few brief remarks about the

1 HCAHPS Survey. It's the first national
2 standardized, publicly reported survey of
3 patient experience of care.

4 Development of the HCAHPS Survey
5 began in 2002. The NQF endorsement came in
6 2005. We nationally implemented it in 2006.
7 HCAHPS results or participation become tied to
8 pay-for-reporting for hospitals beginning in
9 2007.

10 We began the public reporting of
11 HCAHPS scores in 2008. NQF and re-endorsement
12 occurred in 2010, and then the linkage of
13 HACHPS scores to pay-for-performance or
14 hospital value based purchasing, the CMS
15 program, that began in 2012.

16 So once again, HCAHPS is a
17 national, standardized, uniform survey of
18 patient experience. It's widely used. We
19 believe it's becoming more and more
20 influential. It's available in English,
21 Spanish, Chinese, Russian, Vietnamese and
22 Portuguese.

1 For the scores publicly reported
2 just this month, July, which are based on
3 patients' discharge between October of '12 and
4 September of 2013, there were over three
5 million completed surveys and over 4,000
6 hospitals participated.

7 We've seen improvement in HCAHPS
8 scores since the scores were publicly
9 reported. We've seen significant improvement
10 across all ten and soon to be 11 measures in
11 the HCAHPS Survey.

12 And just to mention what those
13 measures are, they are, briefly, communication
14 with nurses, communication with doctors,
15 responsiveness of the hospital staff, pain
16 management, communication about medicines,
17 cleanliness of the hospital environment,
18 quietness of the hospital environment,
19 discharge information, overall rating of the
20 hospital, would you recommend the hospital,
21 and just added last year and will be publicly
22 reported for the first time in December is a

1 care and transition measure.

2 And that is a brief overview of
3 the HCAHPS Survey.

4 CO-CHAIR MERLINO: Any questions
5 on evidence? Very familiar with this one.
6 Comments? Shall we vote and move on? All
7 right, let's vote.

8 MS. ALLEN: So we're voting on
9 evidence, and one yes, two no. Voting starts
10 now. We're still missing a vote. Okay. All
11 votes are in. Seventeen yeses, zero no.

12 CO-CHAIR MERLINO: Okay, moving to
13 performance gap. Any comments, questions?

14 CO-CHAIR PARTRIDGE: I can't
15 remember where these are in the materials
16 submitted to us, but as I have a note, a
17 couple of these are fairly well topped out.
18 We got that table someplace?

19 DR. PACE: So go to 1(b), 1(b)(2),
20 I think, was some --

21 (Off microphone comments)

22 CO-CHAIR PARTRIDGE: Yes.

1 DR. PACE: So just one comment.
2 It's problematic to enter this kind of data
3 into our submission forms so that's why it's
4 a little hard to follow, but the first number
5 is the mean performance.

6 So, for example, communication
7 with nurses, 79.12 would be the average
8 performance across hospitals. And then it
9 goes to the 99th percentile, 95th, et cetera,
10 and the very last number, which is on the
11 second line, is 6. That's the interquartile
12 range.

13 Okay. Just to try to orient
14 people because I know it's kind of hard to
15 follow. So Lee, did you have a specific one
16 that --

17 CO-CHAIR PARTRIDGE: I'm having
18 trouble reading these numbers at this
19 distance.

20 Okay, I think what was happening
21 was I was confused by that chart.

22 DR. PACE: Yes, sorry.

1 CO-CHAIR PARTRIDGE: I was reading
2 some 100s and getting very concerned. But I'm
3 much less concerned. Thank you, Liz.

4 MS. GOLDSTEIN: You're welcome.

5 CO-CHAIR PARTRIDGE: What I'm
6 looking at is some means that in fact show
7 there's plenty of room for improvement.

8 CO-CHAIR MERLINO: Any other
9 questions about performance gap?

10 Chris?

11 MEMBER STILLE: So just in terms
12 of disparities it said that disparities
13 information was calculated but it was in an
14 appendix, and I don't think we have easy
15 access to that. Any sort of rough summary or
16 anything that jumps out?

17 MR. LEHRMAN: Yes.

18 MEMBER STILLE: It would just be
19 good to kind of know.

20 MR. LEHRMAN: We do find racial
21 ethnic disparities on the survey non-Hispanic
22 whites tended to score better than minority

1 groups. But within the same hospital,
2 minority groups, blacks and Hispanics, tended
3 to score higher than white non-Hispanics.

4 The issue, really, is minority
5 patients tend to go to poorer performing
6 hospitals on average than white patients. So
7 we still find differences between Asian
8 patients and white patients, Asian patients
9 are more critical about their hospital
10 experience even within the same hospital, but
11 Hispanics and blacks tend to go to hospitals
12 that on average have poor patient experience
13 for all patients.

14 CO-CHAIR MERLINO: Any other
15 questions? Comments? Okay, should we vote on
16 performance gap?

17 MS. ALLEN: So we're voting on
18 performance gap. One high, two moderate,
19 three low, four insufficient, starting now.
20 All votes are in. Sixteen high, one moderate,
21 zero low, zero insufficient.

22 CO-CHAIR MERLINO: High priority,

1 moving right along. Any comments? Questions?
2 Does anybody think this isn't a high priority?
3 Shall we vote? We might be out of here for
4 lunch.

5 MS. ALLEN: We're voting on high
6 priority. One high, two moderate, three low,
7 four insufficient. Voting starts now. All
8 votes are in. Eighteen high.

9 So Liz is on the phone, and at
10 times she's voting and sometimes she's not.

11 MS. DORIAN: We just missed her
12 vote on the very first one. I didn't get to
13 it in time, but add it in.

14 MEMBER MORT: I am here. I don't
15 think I've missed any vote. Maybe --

16 MS. DORIAN: I think just that
17 first one there was a lag and it came in late.
18 But we'll be sure to add it in.

19 MEMBER MORT: Oh. I was a big
20 fan.

21 MS. DORIAN: Yes.

22 CO-CHAIR MERLINO: Okay,

1 reliability.

2 DR. PACE: And Liz, feel free to
3 comment, you know, we're interested in your
4 thoughts as well.

5 MEMBER MORT: Thank you.

6 CO-CHAIR MERLINO: Moving to
7 reliability. Comments? Questions?

8 DR. PACE: So under reliability we
9 talk about measure specifications as well as
10 the reliability testing. And --

11 MS. GOLDSTEIN: I was going to add
12 I put, actually, I probably should move the
13 Cronbach alphas are over there.

14 MEMBER BRADLEY: I noticed in, I
15 think it was one of the other CAHPS Survey, it
16 mentioned that risk adjustment is not
17 appropriate for these types of measures. It's
18 more case mix. But then you talk about risk
19 adjustment for this CAHPS measure. Is there,
20 kind of what is the philosophy? Do we go with
21 risk adjustment or case mix adjustment or --

22 MS. GOLDSTEIN: Yes. We always, I

1 think the form called it risk adjustment, so
2 it may have lapsed into that word. But we
3 always call it case mix or patient mix
4 adjustment particularly in the hospital where
5 it's called patient mix adjustment.

6 But it's the same for all the CMS
7 surveys. We do adjust for characteristics
8 that influence response tendencies.

9 MEMBER BRADLEY: So in your
10 research where you show that Asian populations
11 don't tend to score as high, would you adjust
12 for that?

13 MS. GOLDSTEIN: We don't adjust
14 for race ethnicity. So we adjust, in the
15 hospital world we're adjusting for age,
16 education, overall health status, their
17 service line, whether it's maternity, surgical
18 or medical, and - self-referred health
19 status. Health status.

20 MEMBER BRADLEY: Okay, thank you.

21 CO-CHAIR MERLINO: Have you looked
22 at the data yet on depression? Are you

1 adjusting for that? Do you see any
2 differences by patients who report, self-
3 report depression?

4 MR. LEHRMAN: We did an item last
5 year to the survey about overall mental or
6 emotional health because of suggestions that
7 perhaps depression or other things weren't
8 being captured by the overall general health.
9 Analysis showed that, which we kind of knew
10 before from our pretesting, but it didn't
11 really add anything to what was explained by
12 overall general health.

13 So we have looked into that but
14 did not find that patient assessment of their
15 overall mental or emotional health impacted
16 the scores more than could be accounted for by
17 overall general health or any other patient
18 mix adjusters.

19 CO-CHAIR MERLINO: So didn't
20 change overall self-reported health, right?
21 Health status?

22 MR. LEHRMAN: It didn't add to the

1 adjustment.

2 CO-CHAIR PARTRIDGE: But going
3 back to Becky's question about a case mix
4 adjustment, CMS makes those adjustments. But
5 if you look at the CAHPS' instructions,
6 you'll see that other users can choose to do
7 that or not.

8 In other words, for your purposes
9 those are a fixed component of these measures.
10 But if Jim decided he wanted to use CAHPS and
11 didn't want to follow the protocol, you
12 wouldn't necessarily have to adjust. If
13 you're reporting it to CMS, you do, and CMS
14 will adjust it. But if you wanted to report
15 it out yourself without the adjustment, you
16 could.

17 MS. GOLDSTEIN: Yes. So for
18 surveys that if you're using it for quality
19 improvement, so to compare your performance
20 over time in your hospital, say, then it
21 really doesn't need to be adjusted unless your
22 patient mix changes dramatically from time

1 period to period.

2 It's when we're using it for
3 public reporting or accountability in
4 comparing hospitals, that's when it needs to
5 be adjusted.

6 DR. PACE: So let me just also,
7 just to get us back on track. We talk about
8 case mix adjustment under validity, so if we
9 could hold that until we get to validity.

10 But Bill, if you want to answer
11 that question.

12 MR. LEHRMAN: Well, I just want to
13 mention that we do report every quarter on our
14 own website, the patient mix adjustment
15 coefficients. So I think you can work
16 backward from those to get the unadjusted
17 scores. We also adjust for survey mode of
18 course, telephone, mail, et cetera, but the
19 hospitals submit the data to us. The data
20 they submit to us is unadjusted, so they have
21 that if that's what they want to work with.

22 CO-CHAIR MERLINO: Any other --

1 Carol?

2 MEMBER LEVINE: Why are patients
3 who go to SNFs excluded? Is it only hospital
4 to home? And are patients under observation
5 status, are they considered to be included?

6 MS. GOLDSTEIN: So in terms of if
7 they go to a nursing home from the hospital,
8 we actually initially included that group of
9 patients. We have over time excluded that
10 group because response rates were really,
11 really, really low for that group. It was
12 very hard to reach them.

13 Often the vendors may not have had
14 the right mailing address, the survey never
15 got to them. If they tried to call the
16 nursing home, the nursing home staff would
17 refuse to transfer them to the patient's room.
18 So response rates, vendors were spending, for
19 a small population were spending a very
20 significant time getting nonresponse. So they
21 eventually were excluded from the survey.

22 MEMBER LEVINE: And a little

1 disturbing, because so many patients now do go
2 to short term rehab. And that is part of the
3 discharge process is did you know where you
4 were going, you know, and all that. But I
5 understand.

6 MS. GOLDSTEIN: Observation
7 patients are excluded from the survey.

8 DR. PACE: So what's up here is
9 the performance measure score reliabilities,
10 and I believe you used the interunit
11 reliability that we mentioned in the notes.
12 And then Liz posted up here, because we didn't
13 have that, the Cronbach's alpha for the
14 patient level scales on the measures that are
15 multi-item.

16 MEMBER BEVANS: Is the discharge
17 info only two items? Could you explain the --

18 MS. GOLDSTEIN: That one's just
19 two items, so that's why that score's pretty
20 low.

21 CO-CHAIR MERLINO: Any other
22 questions?

1 MEMBER NEUWIRTH: This is just for
2 us. Out of curiosity, is there a SNF type
3 CAHPS that we'll be reviewing?

4 DR. PACE: There are three nursing
5 home CAHPS. One for short term, one for long
6 term and one for family members. Those
7 surveys and measures are sponsored by AHRQ at
8 this point in time, and those were part of the
9 list of measures that were not submitted for
10 endorsement maintenance and we will have to
11 follow up with the developers in terms of
12 where we stand with those. But there are
13 three.

14 CO-CHAIR MERLINO: Anybody else?

15 MEMBER NEUWIRTH: I guess I just
16 wanted to echo what Carol said. I think, you
17 know, more and more with elective surgeries
18 and the elderly population getting more
19 elective surgeries, people are going to
20 continue to, you know, go to these short term
21 facilities for rehab, and we're not going to
22 capture them in this way. So I think that's

1 a big gap.

2 MEMBER BRADLEY: Could I just say
3 there's not a CAHPS survey, either, for
4 inpatient rehabilitation hospitals. Are you
5 all working on one of those, for IRFs? A
6 CAHPS survey for IRFs.

7 MS. GOLDSTEIN: There is
8 discussion about that so I'm not sure, you
9 know, what CMS is going to do. The areas that
10 we're working on right now, besides hospice
11 CAHPS which we just finished, we've been doing
12 some testing of an emergency department survey
13 as well as a surgical outpatient for both
14 hospitals and ambulatory surgery centers. So
15 those are the ones that are closest on the
16 horizon.

17 CO-CHAIR MERLINO: Anybody else?
18 Peter?

19 MEMBER THOMAS: As I understand it
20 we will be looking at later in this process,
21 functional measures, and some of those might
22 get to some of the rehab issues, and maybe not

1 IRF specifically, I don't know. But we'll see
2 what the measures are. But am I right about
3 that?

4 DR. PACE: Yes. We will in Phase
5 2 be looking at function measures. It's more,
6 you know, very specific about patient
7 functional status, so it's not experience with
8 care, these type of experience measures from
9 that facility.

10 CO-CHAIR MERLINO: Any other
11 comments? Questions? Shall we vote?

12 MS. ALLEN: We're voting on
13 reliability. One high, two moderate, three
14 low, four insufficient. Voting starts now.
15 Please revote. All votes are in. Results, 14
16 high, 4 moderate, zero low, zero insufficient.

17 CO-CHAIR MERLINO: Validity.
18 Comments? Any more risk adjustment comments?

19 MEMBER STILLE: This is relatively
20 small, but I was wondering in your case mix
21 adjustment had you thought at all, maybe this
22 is the next round thing, about looking at

1 complexity as something you adjust for?
2 There's more sophisticated complexity scores
3 that are going on and people are finding that
4 there's relationships with experience of care.

5 MS. GOLDSTEIN: There has been
6 some work early on with the pilot looking at
7 different variables and looking at, you know,
8 more condition information and more complex
9 models. It didn't really give us anything
10 more in terms of the adjustment. I think some
11 of that's in the published literature too.

12 CO-CHAIR MERLINO: Any other
13 comments? Questions?

14 MEMBER NEUWIRTH: I was confused.
15 The domain area around quiet and physical
16 environment, were those ultimately combined or
17 are they now separated out?

18 MR. LEHRMAN: For public reporting
19 they're separate. Quietness and cleanliness,
20 we did focus group and other testing, and
21 consumers said that they really thought those
22 were very different aspects of the hospital.

1 So initially we were thinking
2 about combining them. We decided not to. On
3 the other hand, for the value based purchasing
4 program we do combine them into what we call
5 the hospital environment dimension in VBP.

6 MEMBER NEUWIRTH: Thank you.

7 CO-CHAIR MERLINO: There was talk
8 at one point about stratifying by hospital bed
9 size. Are you still thinking about that or
10 has there been any other consideration?

11 MS. GOLDSTEIN: That isn't, I mean
12 we wouldn't use it in case mix or patient mix,
13 so it's a hospital characteristic. That's,
14 you know, under the control of the hospital.
15 We haven't had more discussions about
16 stratifying on the website. It just makes the
17 displays fairly complex, and it would have to
18 be done for the clinical measures also,
19 although there's been lots of work currently
20 in CMS going on to try to simplify some of
21 this information for consumers.

22 CO-CHAIR MERLINO: Do you have an

1 idea of how much traffic comes to the website
2 from consumers? I'm just curious.

3 MR. LEHRMAN: We're not sure how
4 many consumers go there, but the hit rates are
5 15,000-20,000 per month, I think, for HCAHPS
6 online. That's our own HCAHPS website.

7 CO-CHAIR MERLINO: That's Hospital
8 Compare?

9 MR. LEHRMAN: For Hospital
10 Compare.

11 MS. GOLDSTEIN: Oh, to get
12 Hospital Compare, you could just put
13 hospitalcompare.gov and --

14 MR. LEHRMAN: Yes.

15 CO-CHAIR MERLINO: So it's about
16 20,000 a month?

17 MR. LEHRMAN: Yes. Not as many
18 consumers go there as we'd like them to.

19 CO-CHAIR MERLINO: Any other
20 questions about validity?

21 DR. PACE: So they submitted some
22 information I think we posted last week in a

1 supplemental form that relates to the
2 correlations at the patient level and then at
3 the hospital level, so Nadine is pulling those
4 up now.

5 So this first one was the patient
6 level. So I'll let Liz or Bill just kind of
7 explain what this represents or what we might
8 take from this.

9 MR. LEHRMAN: Okay, so these are
10 top box correlations at the patient level from
11 patients discharged in the year 2013. The top
12 box is the most positive response in the
13 survey. Typically that's always, nurses
14 always communicated with courtesy and respect,
15 for instance. We find fairly high top box
16 correlations amongst and across the measures.

17 These are all 11 measures
18 including the new care and transition. I
19 guess we'll be talking more about that later.
20 We're pleased the level of correlations.
21 They're high but not too high.

22 We think that these different

1 domains or measures are tapping into different
2 aspects of the patient experience. And a
3 hospital that, the level of correlations is
4 such that we don't believe there's a lot of
5 redundancy or halo effect in the survey.

6 We also submitted, as you
7 mentioned, a little bit late the hospital
8 level top box correlations which are higher
9 than the patient level ones you see here. And
10 also the average top box inter-item
11 correlations which shows, the bottom table
12 that shows the correlations of the individual
13 items that go into these seven composites.

14 As you notice, the nurse with
15 nurse is 0.50 indicating that the items within
16 that nurse composite were more highly
17 correlated with each other than they are with,
18 say, the other six. We call them composite
19 measures which we think is also a good thing.
20 Again, these are all significant at about any
21 level you care to measure at.

22 DR. PACE: Right. So I think that

1 the two that we're most used to seeing are the
2 ones that we talked about, the patient level
3 and the hospital level correlations of the
4 scores.

5 And as Bill was saying, the basis
6 of this is that they would expect them to be
7 correlated because they're all tapping in to
8 an overall idea about experience with care.
9 But, you know, obviously they're not redundant
10 of one another.

11 So then again under validity, if
12 you have concerns about case mix adjustment or
13 exclusions, missing data, that should be in
14 the testing attachment as well. So any
15 questions or comments?

16 MR. LEHRMAN: I would just like to
17 reiterate as Liz said earlier that we do a lot
18 of training. This is the Quality Assurance
19 Guidelines Version 9.0. This is the ninth
20 revision, or eighth revision of the original.

21 We take oversight very seriously
22 as well as training the vendors and individual

1 hospitals' administrative survey, and we found
2 that you almost can't be too specific on how
3 you indicate how things should be done with
4 just about every aspect of the survey to
5 ensure that the results are comparable across
6 hospitals.

7 There are some 50 approved vendors
8 and over 4,000 hospitals doing the survey. So
9 creation of standardization and oversight and
10 training are very important to the health of
11 the survey and the usefulness of the results.

12 CO-CHAIR MERLINO: Any other
13 questions or comments? Should we vote on
14 validity?

15 MS. ALLEN: Voting on validity.
16 One high, two moderate, three low, four
17 insufficient. Voting starts now. All votes
18 are in. Seventeen high, zero moderate, zero
19 low, zero insufficient.

20 CO-CHAIR MERLINO: Feasibility.
21 Comments? There's a lot of experience with
22 this one. Anybody? Questions? Shall we

1 vote? Feasibility.

2 MS. ALLEN: Voting on feasibility,
3 one high, two moderate, three low, four
4 insufficient. Voting starts now. All votes
5 are in. Seventeen high, zero moderate, zero
6 low, zero insufficient.

7 CO-CHAIR MERLINO: Usability and
8 use. No comments? Questions? Come on.

9 All right, if there's no comments
10 or questions we'll take a vote.

11 MS. ALLEN: Voting on usability
12 and use. One high, two moderate, three low,
13 four insufficient information. Voting starts
14 now. All votes are in. Seventeen high, zero
15 moderate, zero low, zero insufficient
16 information.

17 CO-CHAIR MERLINO: All right,
18 moving on to 0228 3-Item Care Transitions
19 Measure.

20 (Simultaneous speaking)

21 CO-CHAIR MERLINO: I almost had us
22 there. All right, any comments overall?

1 MS. ALLEN: We're voting on
2 overall suitability for endorsement for
3 Measure 0166-HCAHPS. One yes, two no. Voting
4 starts now. All votes are in. Results are 17
5 yes, zero no.

6 MR. LEHRMAN: Thank you.

7 MS. DORIAN: Okay, so now we are
8 up to 0228 which is the CTM-3, 3-Item Care
9 Transition Measure from the University of
10 Colorado. And I believe we have Eric Coleman
11 on the line, correct?

12 DR. COLEMAN: Hi, yes. Eric
13 Coleman's on the line.

14 MS. DORIAN: All right, Eric.
15 Welcome.

16 DR. COLEMAN: Thank you. I wish I
17 could be there in person to meet with you all
18 face-to-face.

19 MS. DORIAN: Yes. That would be
20 nice.

21 DR. COLEMAN: Should I just give a
22 quick thumbnail about the Care Transition

1 Measure 3-Item?

2 MS. DORIAN: Yes, perfect. Thank
3 you.

4 DR. COLEMAN: Great. So we have
5 had the privilege of going through the NQF
6 endorsement process twice before. In these
7 cases it was under the hospital care
8 coordination track.

9 We're very excited to be in the
10 Person-and-Family-Centered Care track because,
11 really, the essence of a care transition
12 measure gets to the extent to which patients
13 feel as though they've been prepared for their
14 self-care. We deliberately spent time in the
15 early and developmental phases to co-design
16 this with consumers to make sure that these
17 items resonated with them.

18 As you've heard from Bill and Liz,
19 the 3-Item Care Transition Measure has been
20 incorporated into HCAHPS and we really value
21 the spirit with which they have been
22 collaborating with us. But I think I'll just

1 keep it brief and stop there.

2 DR. PACE: Eric, do you want to
3 just mention the change that you sent us just
4 so everyone knows where you're at in terms of
5 --

6 DR. COLEMAN: Sure. Thank you,
7 Karen. So we, as I mentioned, have had good
8 communication back and forth with the HCAHPS
9 folks. And in order to avoid creating
10 confusion in the field we've really tried to
11 align the specifications of the care
12 transition measure with the way it's being
13 used in HCAHPS.

14 And so the most recent change
15 which came, I think, when Lee Partridge made
16 a very helpful suggestion about a month ago
17 that we should also consider adopting the top
18 box approach to reporting. And we have done
19 that.

20 We've also reached out to our
21 partners who are using these in a performance
22 measurement, performance reporting context, to

1 see if they would be willing to go with us in
2 this direction and they're all in agreement.

3 DR. PACE: Okay, thank you.

4 And just for those who were on the
5 workgroup call that's important, because some
6 of the testing that was submitted on the
7 performance score level was actually from the
8 HCAHPS testing. And so it needed to match the
9 specifications, and so I think that's in sync
10 now.

11 CO-CHAIR MERLINO: Anybody from
12 the call want to talk about it?

13 CO-CHAIR PARTRIDGE: I was on that
14 call. I think there were several of us on the
15 call. This is a measure that the organization
16 that I'm associated with is very, very fond
17 of.

18 We've done a lot of work around
19 patient safety and readmissions, and we happen
20 to think that the three questions that are
21 asked here are pretty relevant to whether or
22 not a patient reappears on your doorstep, and

1 also whether or not the care that they need
2 post-hospitalization is provided.

3 And we did notice that a lot of
4 the work that Eric Coleman and his colleagues
5 have done on the measure and the testing data
6 that we had was different from what would be
7 or might be the results once they were
8 incorporated into CAHPS, the top box score
9 being one of the issues.

10 Another was, as I remember, Eric,
11 you didn't use some of the case mix
12 adjustments that HCAHPS typically uses in --

13 DR. COLEMAN: Yes, that's correct.

14 CO-CHAIR PARTRIDGE: And are you
15 now comfortable with using those case mix
16 adjustments as well in this measure?

17 DR. COLEMAN: We're certainly very
18 comfortable adopting those approaches. I
19 don't know if Bill and Liz are still on the
20 line, but they did share some of their data
21 with us and so we had an opportunity to see
22 just how much the measures fluctuated under

1 that kind of adjustment. It's pretty modest.
2 But in the spirit of alignment, we'd be happy
3 to go that route too.

4 DR. PACE: Right. But for right
5 now what you submitted was just the scoring,
6 not adding the case mix adjustment, correct?

7 DR. COLEMAN: We have not sent
8 that in yet.

9 DR. PACE: Right.

10 DR. COLEMAN: We had understood
11 that it probably would be a source of
12 discussion on this call and we discussed it as
13 a team are very open to that, submitting that
14 as an amendment or how ever you would call it.

15 CO-CHAIR MERLINO: Anybody else on
16 the call that wants to comment? From an
17 operational standpoint I think this is a very
18 important measure. It's a gap that we need to
19 fill.

20 DR. PACE: So should we start with
21 evidence then? This is something that
22 hospitals and other providers can influence.

1 Do people agree, or any comments on that?

2 CO-CHAIR MERLINO: Chris?

3 MEMBER STILLE: Just real quickly,
4 from the pediatric perspective it's at least
5 as important if not more important. So I'd
6 encourage a version for child health to be
7 developed as well.

8 DR. PACE: Eric, are pediatric
9 excluded?

10 DR. COLEMAN: You know, I'm really
11 glad that question's been brought up. We from
12 the beginning saw this as really expanding
13 across the age spectrum. And again in the
14 interest of being aligned with HCAHPS we did
15 add the 18 and older.

16 However, in order to try to create
17 balance in the universe we've been working
18 closely with our colleagues in Boston who are
19 trying to create a more pediatric oriented
20 version of this and sharing our materials,
21 literally, with them hoping that they'll one
22 day be before you with a pediatric version.

1 DR. PACE: And actually, tomorrow
2 we're going to be looking at a child HCAHPS.
3 So I think that's a good question that we can,
4 I didn't think of that before.

5 CO-CHAIR MERLINO: Carol? Oh,
6 Sherri?

7 MEMBER LOEB: I agree with Chris.
8 You know, inpatient HCAHPS is really
9 important, but transitions of care, you know,
10 once you're home is what we need to prevent
11 readmissions and keep the patients safe once
12 they're out of the hospital. So it's really
13 vitally important.

14 CO-CHAIR MERLINO: Any other
15 comments? Can we vote on evidence and then
16 get more granular? All right, let's vote.

17 MS. ALLEN: We're voting on
18 evidence. One yes, two no. Voting starts
19 now. The results are in. Seventeen yes, zero
20 no.

21 CO-CHAIR MERLINO: Okay, moving to
22 performance gap. Lee, do you want to kick it

1 off with a comment?

2 CO-CHAIR PARTRIDGE: No, I don't
3 have a comment on this one.

4 CO-CHAIR MERLINO: Anybody?
5 Comments, anybody else on the call? So staff
6 notes? Pretty good?

7 DR. PACE: Right. So Eric, for
8 the performance score you basically had the
9 information from Maine's utilization. And so
10 I don't know if you want to make any comments
11 about performance gap.

12 DR. COLEMAN: Sure. I do
13 appreciate the comments that were shared
14 earlier about chances are in our professional
15 lives and in our personal lives we all can
16 point to times when the experience of
17 discharge from the hospital, particularly with
18 the focus on self-care, hasn't gone as well as
19 we would have liked.

20 Our experience in the state of
21 Maine, and we're also working with CMS under
22 the Community Based Care Transitions Program

1 that's out of CMMI, you know, we are finding
2 consistently, I guess, the nice way to say it
3 is room for improvement among the earlier
4 HCAHPS testing.

5 And I don't know, again, if Bill
6 and Liz are still on the line, but among all
7 the subcomponents of HCAHPS the care
8 transition measure scores are the lowest.

9 And when we look at areas around
10 safety, when we look at areas around quality,
11 and then I think when we really start getting
12 into the nuts and bolts of what the patient
13 experience is like, which is really the thrust
14 of the program that I run in Colorado, I think
15 for the most part that this is an area that
16 really warrants greater attention from the
17 performance standpoint.

18 CO-CHAIR MERLINO: Any comments or
19 questions? Concerns? I think we can vote.

20 MS. ALLEN: Voting on performance
21 gap. One high, two moderate, three low, four
22 insufficient. Voting starts now. All votes

1 are in. Sixteen high, one moderate, zero low,
2 zero insufficient.

3 CO-CHAIR MERLINO: Okay, moving to
4 high priority, I would just add what Chris
5 says. This isn't just satisfaction, this is
6 safety and quality as well. This is a huge
7 gap coming out of the hospital so it is a high
8 priority. And absolutely, it needs to be in
9 pediatrics. No question.

10 Any comments? Questions? Shall
11 we vote? Vote on high priority.

12 MS. ALLEN: Voting on high
13 priority. One high, two moderate, three low,
14 four insufficient. Voting starts now. All
15 votes are in. Seventeen high, zero moderate,
16 zero low, zero insufficient.

17 CO-CHAIR MERLINO: Okay,
18 reliability. Karen, any comments?

19 DR. PACE: Eric submitted the
20 patient-level instrument reliability. And I
21 guess, Eric, there were two different results
22 were presented, 0.8 and 0.93. It said that

1 was for four factors, but it was a little
2 unclear what you were presenting. So maybe we
3 can just go to the testing attachment and you
4 can clarify that for us.

5 DR. COLEMAN: Yes. Thank you,
6 Karen. And we realize that it's the pros and
7 cons of having been around a little bit that
8 we have in doing different types of testing
9 over time.

10 As Karen mentioned, our most
11 recent testing looks at Cronbach's alpha 0.80
12 and a Spearman-Brown reliability of 0.84.
13 That was in collaboration with our HCAHPS
14 colleagues. In some of our other work, we
15 have identified a Cronbach's alpha as high as
16 0.93.

17 And one of our, I think just to
18 the question about how the measure performed
19 in more diverse populations, we did the study
20 where we deliberately oversampled people,
21 African Americans, Hispanic American and folks
22 in rural dwelling areas, where we found very

1 high Cronbach's alpha, in this case 0.94 in
2 African Americans, 0.93 in Hispanic Americans,
3 0.96 in rural dwelling adults. And so that
4 might explain a little bit of the earlier
5 confusion.

6 DR. PACE: Okay. Thank you. And
7 can you just clarify what this meant about
8 four factors?

9 DR. COLEMAN: Yes. There was the
10 three factors each related to the three items
11 and then there was sort of an overarching
12 factor. And I'm sorry, I'm scanning to figure
13 out which page I share that with you. But the
14 reason why there were three items in four
15 areas was that one was sort of a cross-cutting
16 factor, cross-cutting characteristic.

17 DR. PACE: CTM, what you're
18 presenting for endorsement is three items,
19 correct?

20 DR. COLEMAN: Three items, yes.

21 DR. PACE: Okay. All right.

22 CO-CHAIR MERLINO: Comments?

1 Questions? Oh, sorry. Dawn?

2 MEMBER DOWDING: Could I just
3 clarify? And I might have missed this, but am
4 I right in thinking that you've just changed
5 the way in which you score the CTM? So it's
6 gone from an average rating to a top box
7 rating.

8 So the data that we're looking at,
9 is that being calculated for the top box
10 scoring or is it on the old way of scoring?
11 Because I know there might not be a
12 difference, but it is important for us to
13 understand.

14 DR. COLEMAN: No, I appreciate it
15 and I'm glad you brought that up because we
16 are a little bit in a transition phase
17 ourselves in terms of the work that we're
18 presenting.

19 You know, essentially in the
20 earlier days we did present this as a score
21 that was standardized to a 0-100 scale, a
22 linear transformation, if you will. And then

1 as time has evolved and we've followed where
2 HCAHPS is going, we have tried to align with
3 them using the top box approach. The material
4 that go into both calculations are the same.
5 It's really sort of how the information is
6 being presented.

7 But the earlier work we did was
8 based on a 0 to 100 linear transformation
9 score, and the more recent work is using the
10 top box approach. And we're very comfortable
11 using that top box approach from here forward
12 to be, as Lee suggested, to avoid creating
13 confusion in the field.

14 DR. PACE: So let me just clarify.
15 The Cronbach's alpha there is at the patient-
16 level instrument, so that isn't affected by
17 the hospital scoring. And the hospital-level
18 reliability that they presented is based on
19 the top box scoring because it's data that was
20 shared from the HCAHPS data that they
21 presented. Is that correct, Eric?

22 DR. COLEMAN: Yes. Thank you,

1 Karen.

2 DR. PACE: Okay.

3 CO-CHAIR MERLINO: Any other
4 comments? Dawn, you're good? All right,
5 should we vote on reliability?

6 MS. ALLEN: Voting on reliability.
7 One high, two moderate, three low, four
8 insufficient. Voting starts now. All votes
9 are in. Results, 13 high, 3 moderate, 1 low,
10 zero insufficient.

11 CO-CHAIR MERLINO: Okay, validity
12 testing.

13 DR. PACE: So let's see. Eric,
14 maybe you could tell us how you did validity
15 testing of the patient-level instrument. It's
16 like you -- oh, I see what you did. You
17 compared patients who had ED or
18 rehospitalization to those who hadn't, to look
19 at this is what we call known groups' validity
20 testing.

21 So you have a group that had ED
22 and rehospitalization visits and you expect

1 that maybe they had a different care
2 transition experience than those who were not
3 readmitted and what the difference was. So
4 Eric, do you want to say anything more about
5 that?

6 DR. COLEMAN: Yes. No, that's
7 absolutely right. We thought since again kind
8 of back to first principles, if really the
9 three items are telling us the extent to which
10 hospitals help prepare these folks for what
11 they were going to experience after they left
12 the building, hospitals that did a better job
13 should expect fewer people to have to come
14 back again. And so Karen's right on the dot.

15 We also did another level of
16 validity where we knew something about the
17 hospitals that we were comparing. So we chose
18 hospitals that were part of a larger umbrella
19 organization for which we already had a fair
20 amount of insight into who does a really good
21 job in this area and who didn't.

22 And so we were able to then again,

1 you know, with the added insight of what went
2 on kind of underneath the hood we were also
3 able to do another form of validation and
4 write that up for publication that CTM was
5 able to discriminate among the hospitals in
6 the way that you would have guessed based on
7 knowing which hospitals do a better job in
8 this area and which didn't.

9 So we had a fair level of
10 insider's information, if you will, about how
11 these hospitals performed then allowed us to
12 step back, test the measure as though we were
13 sort of objective and then look at the
14 results.

15 DR. PACE: And then for the
16 computed performance score using this top box
17 method, you submitted again the analysis that
18 was from HCAHPS where you looked at the
19 correlation of the care transition measure
20 with the other measures within the HCAHPS set.

21 DR. COLEMAN: That's correct.

22 DR. PACE: Okay.

1 CO-CHAIR MERLINO: Comments or
2 concerns? Estee?

3 MEMBER NEUWIRTH: This is Estee
4 Neuwirth and I'm a huge fan of transition
5 support. I guess I'm wondering to what extent
6 these measures have been harmonized with the
7 HCAHPS particularly with the discharge section
8 of HCAPHS, which seems so comparable.

9 So I'm wondering, you know, how
10 distinct are these and what kind of testing
11 has been done to distinguish the power of each
12 of these different elements of the HCAHPS
13 measure and of the CTM measure, and in
14 particular just because I'm wondering about
15 sort of duplicative issues.

16 DR. COLEMAN: Yes, and thank you.
17 And just to sort of time travel together back
18 a number of years, when HCAHPS first came out
19 we had some concerns about the discharge items
20 within HCAHPS. And because those folks had
21 been so collaborative we also were able to see
22 how those discharge items were performing.

1 And we had a hunch that our CTM-3
2 items and the HCAHPS discharge items were
3 measuring different constructs. We did do
4 some head-to-head comparison. I'm happy to
5 share that document with the group.

6 We didn't go forward to publish it
7 because we, again this was done, really, I
8 think, for us to then have another
9 conversation with the HCAHPS developers about
10 whether CTM might complement the existing
11 structure.

12 But I will just share the Cliff's
13 notes version is that we were able to
14 demonstrate that the two former discharge
15 planning items are different than the three
16 CTM items when we looked at different forms of
17 validation. And if that's a document that the
18 committee would like to look at I'm happy to
19 share that. I think we submitted this with
20 our earlier endorsement attempt.

21 DR. PACE: I need to try to pull
22 it up. Do you have offhand the correlation

1 between the, in HCAHPS, the CTM or the care
2 transition and the discharge performance
3 measures?

4 DR. COLEMAN: I'm trying to pull
5 them up, and by the way the hold music is not
6 coming from us. Again our goal was not to
7 poke holes into HCAHPS but it was to show that
8 there probably was a different --

9 MEMBER NEUWIRTH: I'd be
10 interested in seeing that. And I'm curious if
11 other organizations have done any inquiry into
12 this. We're actually just at Kaiser
13 Permanente starting to do some comparisons of
14 this, and I don't have the results of that yet
15 but I'd be curious if others around here in
16 terms of the use are experiencing additional
17 power from the CTM-3.

18 DR. COLEMAN: Karen, I do have the
19 document. It's from March 14th, 2006.

20 DR. PACE: Why don't you just tell
21 us.

22 DR. COLEMAN: Yes, I'm skimming

1 through to find a better answer to the
2 question.

3 DR. PACE: Right. Bill came to
4 the microphone so he can tell us quickly.

5 DR. COLEMAN: Thank you, Bill.

6 MR. LEHRMAN: In the supplemental
7 information we submitted a week or two ago,
8 the top box correlation between the discharge
9 composite and care transition is 0.29. So
10 again it's a moderately positive correlation,
11 but a lot of difference between, we think,
12 what those two sets of items measure.

13 DR. PACE: Thank you.

14 CO-CHAIR MERLINO: Any other
15 questions? Eric, were you going to say
16 something else?

17 DR. COLEMAN: No, I think Bill's
18 answer's better than what I had teed up.

19 CO-CHAIR MERLINO: He works for
20 the government. Anybody else? Questions?
21 Should we vote on validity? All right.

22 MS. ALLEN: Now we're voting on

1 validity. One high, two moderate, three low,
2 four insufficient. Voting starts now.

3 Twelve high, three moderate, one
4 low, zero insufficient.

5 CO-CHAIR MERLINO: All right,
6 feasibility. Actually I see feasibility and
7 usability almost connected because this is a
8 plug and play for HCAHPS with maybe the
9 exception of Estee's comment about is it
10 duplicative for the discharge question. But
11 I mean this could be bolted on the back of the
12 survey and I think pretty much used in the
13 same fashion.

14 DR. PACE: Right. And I think the
15 other thing is that for organizations not
16 using HCAHPS they can use this alone. And the
17 correlation we saw that Bill just shared with
18 us, the 0.29, would indicate they're related
19 but not duplicative, that they're not
20 redundant.

21 So feasibility? Any comments
22 about feasibility issues? Okay.

1 CO-CHAIR MERLINO: Ready to vote.

2 MS. ALLEN: We're voting on
3 feasibility. One high, two moderate, three
4 low, four insufficient. Voting starts now.
5 All votes are in. Sixteen high, zero
6 moderate, zero low, zero insufficient.

7 CO-CHAIR MERLINO: Usability and
8 use. Does anybody think this won't be used?
9 Comments? Questions? Anybody from the
10 committee? Shall we vote?

11 MS. ALLEN: We're voting on
12 usability and use. One high, two moderate,
13 three low, four insufficient information.
14 Voting starts now. We're still waiting on a
15 vote. All votes are in. Fifteen high, one
16 moderate, zero low, zero insufficient
17 information.

18 CO-CHAIR MERLINO: Overall
19 suitability. Any overall comments, questions,
20 concerns? Vote.

21 MS. ALLEN: Overall suitability
22 for endorsement of Measure 0228 3-Item Care

1 Transition Measure, one yes, two no. Voting
2 starts now. All votes are in. Results, 16
3 yes, zero no.

4 CO-CHAIR MERLINO: Thank you,
5 Eric.

6 DR. COLEMAN: Thanks, everyone.
7 Thanks for inviting us.

8 CO-CHAIR MERLINO: Public comment.

9 MS. DORIAN: Operator, would you
10 mind opening the line for public comment
11 please.

12 OPERATOR: Yes, ma'am. If you'd
13 like to make a comment, please press star then
14 the number 1 on your telephone keypad. Okay,
15 and at this time there are no public comments.

16 MS. DORIAN: Okay, thank you. And
17 are there any public comments from the
18 audience? All right, so we're early. We're
19 ahead of schedule. Did you want to use some
20 of the time to do discussions about --

21 DR. PACE: Right. We were
22 thinking not a good idea to start a new

1 measure at this late time, and plus our
2 developers are not expecting us until tomorrow
3 to get into the other measures.

4 But not knowing how our time will
5 go tomorrow, would you be willing to have a
6 little bit of the discussion about feedback
7 and suggestions based on your experience
8 today? And then if we have time tomorrow
9 we'll certainly continue that.

10 But maybe just some of your
11 observations, you know, some of the things I
12 teed up this morning about multiple measures
13 in one submission. If you have thoughts about
14 what worked and what didn't work, you know,
15 the process of evaluating measures, what was
16 useful, not useful.

17 So we're certainly open to
18 suggestions, and we'll maybe just take a few
19 minutes now, because who knows how our time
20 will go tomorrow. And I'll let Lee and Jim
21 start us off.

22 CO-CHAIR PARTRIDGE: Yes, I will.

1 I think for a number of us this is new, and
2 Chris, for everybody the PRO-PM process is new
3 and I realize it's very new for the
4 developers. I think from the perspective of
5 someone who's confronting all this
6 information, and trying to make some
7 assessment as a member of the committee, it
8 would be useful if we could be tougher on the
9 developers at the outset.

10 If when the staff looks at it you
11 don't see the answer in the obvious place, ask
12 the developer to identify it for you, and then
13 we won't all have to go through hyperlinks in
14 trying to find it. I don't know whether
15 that's feasible, but it's almost, if we can't
16 find it we're not going to consider it.

17 And I don't want to be that
18 mean because I know it's hard from the
19 developer perspective putting this whole
20 package together. So it would be helpful, I
21 think, from my perspective as a reviewer.

22 MEMBER DOWDING: I would like to

1 see some sort of two-page summary which
2 basically says we are seeking approval for
3 these measures which comprise of X items. This
4 is the individual patient-level reliability
5 and validity. This is the organizational
6 performance level reliability and validity.
7 This is how many patients we've tested it on.
8 This is the disparity information, if there is
9 any, and this is where it's currently being
10 used.

11 Just as a summary, just so that
12 we're not having to try and seek through, like
13 you've got the alternative, if somebody's
14 given you the kitchen sink and you're trying
15 to figure what the reliability data is you're
16 supposed to be looking at, or you don't have
17 what you need.

18 And I think some sort of very
19 short two-page summary. They can give us the
20 calculations behind it, but just the
21 information we need, just as an overview,
22 would be very helpful.

1 MEMBER LOEB: I would absolutely
2 agree. It's almost the equivalent of an
3 abstract when you're submitting a paper.
4 There's an abstract first that kind of gives
5 you a summary of it. Because for me I mean
6 this is totally new, totally foreign, and
7 hunting through everything and the fact what
8 you said, Lee, of not having it there and then
9 going back and waiting for them to submit it.

10 I mean when you go and submit
11 a paper you have, you know, one chance. And
12 it is hard. You don't want to be nasty, but
13 it needs to be there. And that's a great
14 suggestion of having some type of review. And
15 they've got all the information in there, so
16 I don't think that would be very difficult at
17 all for them to have just a summary analysis
18 for us to take a look at.

19 MEMBER CROSS: I think it would be
20 helpful if we could have, as an appendix, just
21 the survey tool or the questions all in one
22 place. Because a lot of the things that we've

1 read they reference Question 4 or Question 7,
2 and I don't have one easy to place to go find
3 those questions.

4 MEMBER STILLE: Actually one of my
5 three questions was just asked, so that's
6 good. Yes, I think having the instrument
7 right up front would be good. Two other
8 things real quick. One is just have all the
9 stuff about reliability and validity in one
10 place, because not only is it not apparent,
11 you have to go looking in two or three
12 different places for it sometimes.

13 And then the third thing, it would
14 be really nice when we come to meet at the
15 meeting, as much as possible, to not have to
16 give any of the ratings insufficient. You
17 know, if there's something that three or four
18 weeks ahead of time the staff says, wow, this
19 data just isn't ready for prime time, to talk
20 to the developers about that so the developers
21 can get it in.

22 So that when we come here we can

1 say, yes it's good, no it's not good. Because
2 a lot of the time that we spent today was sort
3 of like, we really don't know if it's good,
4 because we don't know if it's there. So that
5 would be great. Thanks.

6 MEMBER VAN ZYL: I think the
7 common theme from the developers was, well,
8 they need more specificity. So I think we can
9 hold them to a higher standard of ease with
10 which we find the information that we're
11 supposed to give an opinion on, but not one
12 developer said, tell me exactly what tests you
13 want me to run on what data. And we can't
14 hold them to that if we don't give them that
15 information.

16 So I think this seems like a new
17 process for a lot of people, but that level of
18 specificity to the developers, I think, would
19 cut down on a lot of confusion on our staff.

20 DR. PACE: I'll just make one note
21 about that. We've had various expert
22 committees that have looked at measure

1 testing, and all of the recommendations are
2 not to be prescriptive, because the measure
3 developers are in the best position to know
4 the best reliability testing for the type of
5 data they have, and the sample they have. And
6 same way with validity.

7 But it is certainly something that
8 we come up against a lot in terms of, you
9 know, requests, just tell me what to do. So
10 it's something that we have to continue to
11 struggle with. And I appreciate what you're
12 saying.

13 Just so, you know, the other thing
14 that we've been trying to do is to be
15 available to the developers to answer any
16 specific questions they have, if they get to
17 a certain item in the question, or want to
18 talk about testing in general.

19 But certainly appreciate the
20 comments and what to do, but that's kind of
21 been the push and pull with more specificity
22 in that the experts tell us, you know, it's

1 impossible to really envision every kind of
2 situation. Because it's a matter of the
3 combination of data, the type of measure, how
4 it's constructed, the data source, you know,
5 so there's a lot of variables that go into
6 picking a particular test. But certainly
7 we're willing to help developers any way we
8 can to give them suggestions.

9 But, you know, one of the things
10 that we could do, which is what we've kind of
11 provided to you, is just say, you know, the
12 most common approach we see is this, not
13 saying it's required, but at least that might
14 be more useful as well.

15 MEMBER VAN ZYL: The second
16 comment I have is related, I think. For many
17 of us, interpreting a Cronbach's alpha is
18 tough since we are several years out from our
19 stats courses.

20 You know, a two-page glossary of
21 common terms would be really helpful, you
22 know, distinguishing type 1 from type 2 error,

1 distinguishing reliability from validity, and
2 just a quick definition of those terms, I
3 think, would be very helpful for those of us
4 who are more clinical, and less measure
5 develop-y ourselves. That's a word, I've
6 decided.

7 CO-CHAIR PARTRIDGE: And Chris,
8 you said you had three questions and I think
9 I cut you off after one. No? All right.

10 Carol Levine?

11 MEMBER LEVINE: I agree with
12 everything that's been said, particularly the
13 abstract idea. Just get us, I mean I'm used
14 to reading JAMA and all of the other journals.
15 I can understand fairly quickly what's going
16 on here.

17 This just, you know, is very hard
18 for me. In addition to all of the other
19 things that were said, and I said this earlier
20 but I want to repeat it, that I would like to
21 encourage the developers to think about the
22 kinds of questions that are going to come up,

1 and answer them ahead of time, like the
2 questions of diversity and ethnicity, and the
3 questions of why did you pick these inclusion
4 criteria? Because they're going to be asked,
5 so it would be better if they thought about
6 those things ahead of time.

7 There may be other things as well.
8 I sort of lost the sense of the people in all
9 of this process, and I'd want to know, you
10 know, I think that's what this is about. And
11 so we need to understand that a little bit
12 better. Thank you.

13 Well, one other idea. Sometimes
14 when you submit, for instance, when you submit
15 a grant proposal, often you will see one page
16 that says, have you done this, done that, done
17 this, where is it? You know, so it's a kind
18 of reminder that these are all the things that
19 are essential to include so you make sure that
20 they're in there somewhere. Doesn't say where
21 they have to be, but they have to be there.

22 **MEMBER BIERNER:** So that would be

1 like a checklist. But I think it would be
2 nice to have in, whether it's in a summary, or
3 in the document, what is their intended
4 audience? We know for some of these that are
5 CMS related that they're mandating them, but
6 for many others, you know, what does the
7 developer envision as the intended users of
8 the instrument?

9 CO-CHAIR MERLINO: Sharon?

10 MEMBER CROSS: Can I ask a process
11 question just about something that we did
12 today? So the one that we discussed where we
13 only approved the three measures and not the
14 other three, and those will maybe come back to
15 us, will we have the information or a summary
16 of the discussion that we did have already, so
17 that we have that available to us, or we will
18 be kind of having that whole discussion all
19 over again?

20 CO-CHAIR PARTRIDGE: There will be
21 a transcript of this meeting. But I think
22 it's a good suggestion and, Lauralei, maybe

1 you can tee up the relevant segment for us.
2 Because at CSAC we often go back and read
3 those transcripts, and they're long.

4 MS. DORIAN: Well, the transcript
5 will be summarized and eventually compiled in
6 a report so we'll have that. I'll be sure to
7 bring it up section by section.

8 CO-CHAIR PARTRIDGE: What Sharon's
9 talking about is likely to come up on our
10 conference call in another, what, four weeks
11 or so. And if you can just pull the
12 discussion, or say if you want to refresh your
13 memory it's pages buh-bum through buh-bum.

14 CO-CHAIR MERLINO: Liz?

15 MS. GOLDSTEIN: I was just going
16 to add, as from a perspective of a developer,
17 I think it would easier almost if there was
18 one form that, you know, started from the very
19 beginning, the background, and kind of, you
20 know, all the different pieces and then having
21 them multiple forms.

22 At least from the developer

1 perspective, it's extremely confusing what
2 goes where, and referencing other parts. So
3 it almost if you kind of went through each
4 piece, you know, background and rationale for
5 measure, and all of that it would be a little
6 bit easier.

7 I also think the information you
8 gave today about what, typically, you would
9 put in each section, I know there are meetings
10 for the developers. I found, you know, I was
11 on a number of those calls. I found what you
12 did today was so much clearer than the
13 guidance that we had while we were submitting.

14 So it wasn't very clear exactly
15 what you were looking for for validity and
16 reliability and all of that. And I know
17 there's lots of controversy, like for
18 reliability, do you even look at it at the
19 patient level, since mostly surveys are
20 reported not at a patient level, at the
21 provider level?

22 So if it is required to do it at

1 the patient level, kind of giving the
2 rationale for that so developers understand.
3 And that's, you can't proceed without, whether
4 you agree or not given there's lots of
5 controversy, you need it, no matter what.
6 So I think giving some of that guidance early
7 on would have been extremely helpful. I feel
8 like after today I have a much better
9 understanding of what you were looking for
10 than when we were working on the different
11 submissions.

12 MEMBER NEUWIRTH: I just want to
13 thank our organizers, because I think
14 logistically this, you know, went really well
15 and we were even finishing early which is a
16 nice treat. I guess I have a couple of
17 comments. One is, I feel like, you know, I'm
18 new to this so I'm learning what's sort of
19 expected. But one of the things that is
20 surprising me is how little time we're talking
21 about use.

22 And so, as part of pre-work we

1 could be asked to find out, I know we're
2 representing ourselves, but many of us come
3 from organizations or are involved in other,
4 you know, health care systems and such. We
5 could do more to do some discovery work about
6 how it's being used, what the limits are,
7 from, you know, the experts in our own
8 organizations. And coming from a large
9 organization, I think I could have done some
10 more pre-work. So that's like something that
11 it's good for me to know, and that I will use
12 moving forward.

13 And I feel like, sort of to your
14 point about the people end of this, you know,
15 it's the people in the organizations that feel
16 really missing here about we spent, I think,
17 like to me it feels like 80-plus percent on
18 reliability and validity, and very little time
19 on use.

20 So I'd love to see, you know,
21 that's really the goal here is to get these
22 measures to be used, to drive performance

1 improvement. And I don't know what kind of a
2 process there has been in the past of could be
3 moving forward to devote, you know, adequate
4 energy, resources and time on the use element
5 of this.

6 And then for me, related to that
7 is, you know, the interconnectedness of these
8 measures. And so I think I mentioned this at
9 the beginning, having some sort of a landscape
10 or thumbnail sketch of what we're going to be
11 doing over the next two years, and the
12 landscape of what exists in patient and family
13 centered care so we can see where the gaps
14 are, so we can see where there's overlap and
15 interconnection, and so then we can also go
16 back to our own organizations, and better
17 educate them about what exists and how to
18 continue to drive use, if they're not using
19 some of these measures.

20 So I think there's tremendous
21 potential here, and it's been a really eye-
22 opening day for me and I want to thank you for

1 orchestrating it all so smoothly and I'm
2 looking forward to, you know, continuing to
3 get to know my colleagues here as well.

4 MEMBER BEVANS: Yes, I wanted to
5 address, I think I'm remembering this
6 correctly, so please correct me if I'm not, a
7 specific question that you posed in the very
8 beginning about the value of asking instrument
9 developers to provide information about the
10 perceived importance. Is that right?

11 DR. PACE: It was about the
12 specific question for the PRO-PMs about how
13 they involve patients or families in
14 identifying what would be of value and
15 meaningful to them.

16 MEMBER BEVANS: I just want to
17 respond to that specific inquiry to say that
18 I think that is absolutely key, I think,
19 particularly as the patient and family
20 centered PRO people. You know, we should
21 really be encouraging folks to, you know,
22 evaluate that. It's something that has, for

1 a long time, for whatever reason, been missing
2 from instrument development, especially from
3 PRO development.

4 The notion of asking the end
5 users, you know, patient or family members
6 what actually, you know, what does transitions
7 to care mean to you, and prioritizing those
8 different concepts to ensure that whatever
9 we're measuring, okay, it's reliable and
10 valid, but does it mean anything? Is it
11 actually meaningful?

12 And so I just wanted to kind of
13 respond and give my little soap box about
14 that. I think it's really important,
15 particularly for this committee who is charged
16 with ensuring, I think, that patients' and
17 families' perspectives are integrated into
18 quality measurement, that people are not
19 responding to that is not a good reason to
20 exclude it from the criteria.

21 I think often people don't know
22 how to respond to that and so, you know, maybe

1 giving them some ideas of what could be done.
2 In fact, I think we saw a couple examples
3 today of qualitative methods that actually
4 answered that question, but it seems like
5 people didn't really know that the focus
6 groups they had done or the consulting they
7 had done with patient and family advisors
8 actually provides evidence for the importance
9 of the concepts.

10 DR. PACE: And I would ask you, so
11 the question I have about that is so how much
12 information there would be useful? Because
13 obviously all of these experience with care
14 measures that used some type of focus group,
15 and I think probably most of them said that,
16 you know, we had focus groups and did
17 qualitative interviews, but is that enough for
18 them to say that or what level of detail and
19 how that relates now to what the end product
20 is that's being submitted for endorsement?

21 And that's what I'm trying to, you
22 know, in order for us to give better guidance

1 to the developers I'm just curious of what
2 your thoughts are about that.

3 MEMBER BRADLEY: Well, I guess for
4 those of you that are really true researchers
5 and maybe you can answer this, but it seems
6 some of the measures that are coming up now,
7 the research is so old or so dated, and it
8 seems that patients' and families'
9 expectations have changed over the last ten
10 years.

11 So if we're basing measures on
12 research that was gathered ten years ago, it's
13 almost like should it be updated somewhat or
14 before we move forward? And is there sort of
15 a rule of thumb of if it's over 20 years old
16 or 15 years old, maybe we shouldn't look at
17 it?

18 DR. PACE: Well, it's a good
19 question. And, you know, for example,
20 clinical, you know, more clinical measures or
21 clinical process measures, that is one of the
22 reasons that we do endorsement maintenance

1 because clinical evidence may change over
2 time. And it's a good question for us to kind
3 of also ponder of, you know, whether this
4 patient and family kind of discussions needs
5 to be updated, and is that what we should be
6 considering evidence for --

7 MEMBER BIERNER: No, I wouldn't
8 want us to try to make them redo everything.
9 I mean you want to kind of have an update of
10 these questions still as relevant, you know,
11 maybe things have changed in the delivery of
12 care in some way that the question that might
13 have been relevant ten years ago isn't as
14 relevant. And then if there's been any
15 expansion of their data collection, you know,
16 additional institutions or hospitals or other
17 facilities that they know of or published, you
18 know, would be useful.

19 MEMBER NEUWIRTH: I think to
20 Katherine's point, maybe in the abstract a
21 simple question of how were patients and
22 families engaged in developing this measure

1 with simple responses like, focus groups were
2 conducted on X date with the following domains
3 of inquiry, relevance, you know, question
4 construct and so on.

5 I mean I think that just knowing
6 what was asked is important too, because it's
7 not enough to ask patients, do these questions
8 make sense, but we need to know are they
9 relevant to them. And also like as someone
10 mentioned, we need to know when these
11 questions were asked, because care for
12 patients on dialysis has changed in the last
13 ten years, and their expectations have
14 changed.

15 CO-CHAIR MERLINO: Debra?

16 MEMBER SALIBA: Thank you. Again
17 I want to echo congratulations for managing a
18 lot of complex materials. I'm also going to
19 echo a couple of other comments. I do think
20 having a single integrated report on the
21 measures would be really helpful as a reader
22 of these, as opposed to the multiple different

1 documents. There seemed to be a lot of
2 repetition, and redundancy and it was a pretty
3 heavy reading burden.

4 And Carol mentioned earlier in the
5 day, and several other people have mentioned,
6 it would be really helpful to have the actual
7 items to start with. It just sort of grounds
8 you in what it is you're going to be reading
9 about.

10 And then the abstract approach, I
11 think, would be also useful. And that
12 abstract could include, if it's a revisit or
13 an update of a measure, a specific section of,
14 you know, changes to consider, since last
15 review and that could include some of these.
16 Because some things are still going to stand
17 the test of time.

18 I mean people don't want to be in
19 pain, for example. There's no reason to sort
20 of retest that pain is an important thing for
21 people at the end of life. So there may be
22 some things.

1 And then finally, I found that,
2 you know, the first section, there were too
3 many subdivisions within the important section
4 that sort of led to repetition and that maybe
5 they could just give, you know, we could tell
6 them what all needs to be covered in that
7 section but not make them all be in very
8 discrete sections.

9 Because it ended up being
10 repetitive, I think, in part because as was
11 mentioned by the developers earlier, they
12 weren't even sure what these distinctions
13 were, so they would just sort of give you the
14 same information over and over again in that
15 section. But again I think it was, you know,
16 a lot of material to organize and that you all
17 did a great job trying to get it put together.

18 CO-CHAIR MERLINO: Sherri?

19 MEMBER LOEB: I think we're on a
20 great track by forming Person-and-Family
21 Centered. There are thousands of outcome
22 measures out there. And when one of the

1 conferences I spoke at was with -- I'm totally
2 blanking on it, but he was a big outcomes guy
3 down, and he was talking about outcomes.

4 And my other half of the speech
5 was about, you know, loving and losing, is the
6 current state of measurement really the
7 answer? And, you know, all the outcomes that
8 are out there that are all disease outcomes,
9 yes, they're important, but they don't address
10 the family.

11 And the biggest statement, or
12 change that came with my husband was when he
13 said, you know, for 18 years I've been working
14 on standards and outcomes, and patient safety
15 and quality, and I never realized that it
16 never really took into consideration the
17 patient who's diagnosed with cancer, and
18 there's nothing that really relates
19 specifically to that patient and their circle
20 of care, and their engagement and family
21 centered.

22 So I think this is a great start,

1 and the more we can get important outcomes
2 that really translate to what's important to
3 the patient, other than the medical outcomes,
4 we need to keep fighting for that.

5 CO-CHAIR MERLINO: I just want to
6 make a couple of comments, and it goes back to
7 what Carol said earlier of why we're here. We
8 are here for the patient. This is the
9 patient's voice that gets translated in a very
10 objective fashion back to the way we run
11 hospitals and health care systems and home
12 health agencies, and whatever it is we do in
13 health care. So it's very, very important to
14 keep that in mind.

15 And secondly, just to add on to
16 what everybody has said, it's great work by
17 the staff. It's a lot of information. But
18 also, thank you for all of your hard work. I
19 mean this is a lot of hard work.

20 And I remember telling Karen and
21 Lauralei when I first got asked to
22 participate, oh my god, I didn't realize how

1 much time this was going to take. But it is
2 a lot of work, and so thank you for all of
3 your effort.

4 The third thing is be frank.
5 Somebody brought up about, you know, more
6 usability talk. I agree. But we need to make
7 sure that we don't feel squelched and people
8 have their voice. If you have something to
9 say, if you're concerned we're not giving
10 something enough time, yell out. Let's talk
11 about it, because I think it's very important.
12 The things that we adopt are going to be
13 around for a very long time.

14 And then finally, for tomorrow,
15 tomorrow, one thing that I would recommend is
16 that when we get to validity and reliability,
17 we really turn it over to you to comment first
18 to drive that based on the staff
19 recommendation so that, you know, we kind
20 frame what the staff as the experts think, and
21 then open it up for discussion.

22 That would be one recommendation.

1 And any other recommendations for tomorrow to
2 make the process more efficient and effective?

3 CO-CHAIR PARTRIDGE: Get a good
4 night's sleep. Have a good dinner. Don't
5 talk about measures over dinner. I want to
6 just echo, Jim said everything that I was
7 thinking, which is very nice, but I want to
8 echo thanks to Karen and to Lauralei and
9 Nadine for all your hard work.

10 And just to say those of you who
11 haven't had the chance I have had to work with
12 Karen very closely for the last two years
13 probably don't appreciate the tremendous value
14 of the patience with which she took us through
15 all of this today. She will be very much
16 missed.

17 DR. PACE: Thank you. I would
18 just say that, of course, NQF couldn't do any
19 of its work without all of you, so we really
20 appreciate all of the time and effort you've
21 put into this and your suggestions.

22 And, you know, we try to have

1 standardization across all of our measures and
2 projects to the extent possible, but we
3 continue to collect this information from the
4 various committees, and we will make efforts
5 to improve.

6 You know, sometimes we get
7 conflicting information so, for example, many
8 developers like the fact that we've put some
9 things in attachments. It's much easier for
10 them to work with. So we'll just have to
11 continue to try to balance the feedback and,
12 you know, we're always trying to make things
13 better.

14 So definitely we value your
15 feedback and we will continue to try to
16 implement some of these things as we get our
17 next chance of relooking at the measure
18 submission form and how it might flow a little
19 better for both the developers and the
20 committee members.

21 So I'm going to turn it over to
22 Nadine to remind us about dinner for those of

1 you who can make it. I'm pointing to Lauralei
2 and saying Nadine.

3 MS. DORIAN: Well, she has the
4 slide, though. But there again we have Mio,
5 1110 Vermont Avenue, and NQF will reimburse
6 you up to \$36 for dinner. So hope to see some
7 of you there even if you can only come for a
8 drink or, you know, a quick bite to eat.

9
10 Thank you, and see you all
11 tomorrow. We do start half an hour earlier
12 tomorrow, so we have continental breakfast at
13 8:00 and then we begin at 8:30. And you can
14 just leave your voting devices by where you're
15 sitting, and the name tags. You can leave
16 everything there, except probably not your
17 computers. But it'll be there tomorrow.

18 DR. PACE: All right, thank you.
19 And we'll see some of you at 6:00 and the rest
20 of you tomorrow at 8:00.

21 (Whereupon, the above-entitled
22 matter went off the record at 4:53 p.m.)

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C E R T I F I C A T E

This is to certify that the foregoing transcript

In the matter of: Person- and Family-Centered Care
Standing Committee Meeting

Before: NQF

Date: 07-28-14

Place: Washington, DC

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