

NATIONAL QUALITY FORUM

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PEDIATRIC MEASURES STEERING COMMITTEE

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TUESDAY
DECEMBER 1, 2015

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The Steering Committee met at the National Quality Forum, 9th Floor Conference Room, 1030 15th Street, N.W., Washington, D.C., at 8:30 a.m., John Brookey and Jeffrey Susman, Co-Chairs, presiding.

PRESENT:

JOHN BROOKEY, MD, FAAP, Co-Chair
JEFFREY SUSMAN, MD, Co-Chair
LAUREN AGORATUS, MA, Family Voices NJ*
MARTHA BERGREN, DNS, RN, NCSN, APHN-BC, FNASN,
FASHA, FAAN, College of Nursing,
University of Illinois Chicago
JAMES BOST, MS, PhD, Children's Healthcare of
Atlanta
TARA BRISTOL-ROUSE, MA, Patient and Family
Centered Care Partners
KAREN DORSEY, MD, PhD, Yale University School of
Medicine
JAMES DUNCAN, MD, PhD, Washington University
School of Medicine
MAUREEN EDIGER, Children's Hospital Colorado
DAVID EINZIG, MD, Children's Hospital and
Clinics of Minnesota
DEBORAH FATTORI, MSN, RN, PPCNP-BC, Nemours
Alfred I DuPont Hospital for Children
KERRI FEI, MSN, RN, Blue Cross Blue Shield
Association
JONATHAN FINKELSTEIN, MD, MPH, Boston Children's
Hospital

KAREN HARPSTER, PhD, OTR/L, Cincinnati
Children's Hospital Medical Center

AMY HOUTROW, MD, PhD, MPH, University of
Pittsburgh, Children's Hospital of
Pittsburgh

DAVID KELLER, MD, University of Colorado School
of Medicine

KRAIG KNUDSEN, MD, Ohio Department of Mental
Health and Addiction Services

SUSAN KONEK, MA, RD, CSP, FAND, Academy of
Nutrition and Dietetics

MARLENE MILLER, MD, MSc, Johns Hopkins
Children's Center at JHHS*

JILL MORROW-GORTON, MD, University of
Massachusetts Medical School

VIRGINIA MOYER, MD, MPH, American Board of
Pediatrics

RICARDO QUINONEZ, MD, FAAP, Children's Hospital
of San Antonio

JEFF SCHIFF, MD, MBA, Minnesota Department of
Human Services

KEVIN SLAVIN, MD, FAAP, Hackensack University
Hospital/Joseph M. Sanzari Children's
Hospital

CAROL STANLEY, MS, CPHQ, Commonwealth of
Virginia, Department of Medical Assistance
Services

JONATHAN THACKERAY, MA, FAAP, Ohio Department of
Medicaid

NQF STAFF:

HELEN BURSTIN, MD, MPH, Chief Scientific Officer

ELISA MUNTHALI, MPH, Vice President, Quality
Management

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

NADINE ALLEN, MEd, Project Manager

SEVERA CHAVEZ, Project Analyst

KAREN JOHNSON, Senior Director

ROBYN NISHIMI, PhD, Senior Consultant

SUZANNE THEBERGE, MPH, Senior Project Manager*

ALSO PRESENT:

NAOMI BARDACH, MD, University of California, San
Francisco

CASEY LION, MD, MPH, Seattle Children's Research
Institute

RITA MANGIONE-SMITH, MD, MPH, Seattle Children's
Research Institute

GREGORY SAWICKI, MD, MPH, Boston Children's
Hospital

RAMESH SACHDEVA, JD, MD, PhD, MBA, AHRQ

MARK SCHUSTER, MD, MPH, Boston Children's
Hospital

SARA TOOMEY, MD, MPH, MPhil, MSc, Boston
Children's Hospital

DONNA WOODS, EdM, PhD, AHRQ

* Present by Teleconference

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

2 (8:36 a.m.)

3 CO-CHAIR SUSMAN: Well, good morning.
4 I'm Jeff Susman one of the co-chairs.

5 CO-CHAIR BROOKEY: And I'm John
6 Brookey, the other co-chair. So, good morning,
7 everyone.

8 CO-CHAIR SUSMAN: Just want to welcome
9 everybody on this rainy day, but just think it
10 could be snow, so this is the better part of
11 evil. It is really a pleasure to see such a
12 great group around the table.

13 We've got a lot of important work to
14 do. And fortunately, the NQF staff is always has
15 made this just a very easy task that can move us
16 through the work as quickly as possible.

17 John and I are going to sort of break
18 up our duties. I'm going to start off this
19 morning, but let me see if John wants to add any
20 words of welcome.

21 CO-CHAIR BROOKEY: No. Thank you very
22 much. And we're going to move forward. Marcia

1 is here to do the introductions and disclosure of
2 interest.

3 DR. WILSON: Good morning, everyone.
4 My name is Marcia Wilson. I'm Senior Vice
5 President of Quality Measurement here at NQF.
6 And I'm joined by a number of my colleagues, and
7 we'll make introductions of the NQF staff in just
8 a moment.

9 But the first order of business for us
10 is the disclosure of interest. And typically,
11 Ann Hammersmith, our in-house counsel, would be
12 here to do this, but I'm going to take care of
13 this today. So I certainly don't have the script
14 memorized as Ann does, but we shall get this job
15 done.

16 So you did receive a disclosure of
17 interest form when you were seated on the
18 Committee, where we ask you a number of questions
19 about your activities. But today we're going to
20 ask you to orally disclose any information that
21 you believe is relevant to the work of this
22 Committee.

1 So we're specifically interested in a
2 disclosure of interest about work directly
3 related to what the Committee is going to do. So
4 please do not feel you need to summarize your
5 resume. We don't need to do that today. But
6 we're particularly interested in grants or
7 research or consulting, again, only if it relates
8 to the work before the Committee.

9 And also, I would note, it doesn't
10 need to be paid work. You may have served on a
11 committee or done volunteer work that may be
12 relevant and you may disclose that as well.

13 One reminder. You do sit on this
14 Committee as an individual. You don't represent
15 the interest of your employer or the person who
16 may have nominated you.

17 Now, just because you disclose that
18 does not mean you have a conflict of interest.
19 We do oral disclosures in the spirit of
20 transparency and openness, so we're going to do
21 this as a way to disclose and also to introduce
22 yourself, so we're going to start with the

1 Committee members.

2 And I would ask you to state your
3 name, the organization you're with, and if you
4 have anything to disclose.

5 And Jeff, if we might start with you?

6 CO-CHAIR SUSMAN: Sure. So, I'm Jeff
7 Susman. I'm at Northeast Ohio Medical
8 University. I serve as the Dean of College of
9 Medicine. And I have no disclosures to make.

10 CO-CHAIR BROOKEY: Good morning. John
11 Brookey, Kaiser Permanente Southern California.
12 And I have no disclosures.

13 DR. NISHIMI: Robyn Nishimi. I'm a
14 senior consultant to the National Quality Forum,
15 and prior to that, I was the chief operating
16 officer. So, thank you all for your efforts
17 today and for today.

18 MEMBER HARPSTER: I'm Karen Harpster.
19 I'm from Cincinnati Children's. I'm a researcher
20 and occupational therapist there. And I have no
21 disclosures.

22 MEMBER SLAVIN: I'm Kevin Slavin. I'm

1 at the Sanzari Children's Hospital at Hackensack
2 University Medical Center in Northern New Jersey.
3 I'm also with the Council of Children's Hospitals
4 for the State of New Jersey. And I have no
5 disclosures.

6 MEMBER FATTORI: Good morning. I'm
7 Debbie Fattori. I work at the DuPont Hospital
8 for Children where I serve as the Director of
9 Advanced Practice and Ambulatory Nursing. And I
10 have no disclosures.

11 MEMBER FEI: Hi. Good morning. My
12 name is Kerri Fei. I work Blue Cross Blue Shield
13 Association in Chicago, Illinois. Previous to
14 working there, I was at the American Medical
15 Association as a measure developer for the
16 Physician Consortium for Performance Improvement.

17 However, last week, I crossed the
18 five-year mark, so I haven't developed measures
19 in five years. None of the measures that we will
20 be discussing today are their measures, so
21 thanks.

22 MEMBER QUINONEZ: Hi. I'm Ricardo

1 Quinonez from the Children's Hospital San Antonio
2 where I am the chief of the Division of Hospital
3 Medicine. And I have no disclosures.

4 MEMBER BERGREN: Hi. I'm Martha
5 Bergren. I'm from the University of Illinois,
6 Chicago College of Nursing. And I have no
7 disclosures.

8 MEMBER KELLER: David Keller. I'm the
9 vice chair of Clinical Affairs and Clinical
10 Transformation at the UC-Denver Department of
11 Pediatrics in the Children's Hospital Colorado.

12 And I am -- next week will be joining
13 the Data Safety and Monitoring Board of Dr.
14 Beinman-Smith's organization out in San
15 Francisco. So I was not a prior conflict, but I -
16 - and I have no idea what she's going to have us
17 do, so I actually don't know if we will be
18 involved with the use of her measure, because our
19 orientation called to tell us what we're doing is
20 next week. But I wanted to put that out there as
21 a potential conflict in the future.

22 MEMBER MORROW-GORTON: Jill Morrow.

1 I'm a Senior Medical Director at Mass Health,
2 which is the Massachusetts Medicaid Program, and
3 I'm a developmental/behavioral pediatrician. I
4 work for the University of Massachusetts Medical
5 School. And I have no disclosures.

6 MEMBER EINZIG: I'm David Einzig from
7 Children's Minnesota. I'm a child psychiatrist,
8 also pediatrician by training, current president
9 of Minnesota Society of Child and Adolescent
10 Psychiatry. And I have no disclosures.

11 MEMBER THACKERAY: Good morning. My
12 name is Jonathan Thackeray. I'm a child abuse
13 pediatrician at Nationwide Children's in
14 Columbus, Ohio. I'm also the assistant medical
15 director for the Ohio Department of Medicaid.
16 And I have no disclosures.

17 MEMBER DORSEY: Good morning. I'm
18 Karen Dorsey, and I'm the director of the
19 Division of Reevaluation and Rulemaking at the
20 Center for Outcomes Research and Evaluation at
21 Yale. And we got measures for the other end of
22 the spectrum for Medicare beneficiaries. And I

1 have no disclosures.

2 MEMBER BOST: Good morning. I'm Jim
3 Bost, Director of the Outcome Center at
4 Children's Healthcare of Atlanta. And I have no
5 disclosures.

6 MEMBER BRISTOL-ROUSE: Hi. I'm Tara
7 Bristol-Rouse with Patient and Family Centered
8 Care Partners. I'm a family stakeholder. And I
9 have nothing to disclose.

10 MEMBER KNUDSEN: I'm Kraig Knudsen.
11 I'm with the Ohio Department of Mental Health and
12 Addiction Services. I'm the Chief of the Office
13 of Research and Evaluation there. And I have no
14 disclosures.

15 MEMBER HOUTROW: Hello. I'm Amy
16 Houtrow. I'm a pediatric rehab medicine
17 physician at the University of Pittsburgh
18 Children's Hospital. And I have no disclosures.

19 MEMBER FINKELSTEIN: Good morning.
20 I'm Jon Finkelstein. I'm a general pediatrician
21 and the Vice Chair for Quality and Outcomes in
22 the Department of Pediatrics at Boston Children's

1 Hospital.

2 I do have one disclosure. I'm a
3 faculty member in Boston Children's Center of
4 Excellence for Pediatric Quality Measurement,
5 which has submitted measures for this call, and I
6 am one of the co-leads in development of measure
7 2797, and I'll be recusing myself during
8 discussion of that measure.

9 MEMBER SCHIFF: Hi. My name is Jeff
10 Schiff. I'm the medical director at the
11 Minnesota Medicaid Program at the Minnesota
12 Department of Human Services, and a pediatric ER
13 physician, and the -- I'm the immediate past
14 chair of the, of the Medicaid Medical Director
15 National Network.

16 I do disclose that I'm a co-
17 investigator with Dr. Rita Mangione-Smith on the
18 Seattle Children's Group, so I'll be recusing
19 myself for those measures.

20 MEMBER STANLEY: Good morning. I'm
21 Carol Stanley with Virginia Medicaid. I'm the
22 Quality Improvement Manager for Medicaid Managed

1 Care and CHIP. No disclosures.

2 MEMBER EDIGER: Morning. My name is
3 Maureen Ediger. And I'm here because of the
4 volunteer role I have as an advocate on the
5 Quality and Safety Committee of the Board for
6 Children's Hospital of Colorado. I have four
7 children, and you'll probably hear way more about
8 them than you'd like to, but that's why I'm here.
9 And, other than that, I have no disclosures.

10 MEMBER KONEK: I'm Susan Konek. I --
11 until last week -- last month was the Director of
12 Clinical Nutrition at the Children's Hospital of
13 Philadelphia. I'm a registered dietitian, and I
14 retired. And I'm going to be joining Cincinnati
15 Children's January 4 in Clinical Management again
16 working with the program there. I have nothing
17 to disclose.

18 DR. WILSON: Thank you. And I believe
19 we have two Committee members on the phone this
20 morning.

21 Lauren, are you available to do a
22 disclosure?

1 MEMBER AGORATUS: Yes. Hi, Lauren
2 Agoratus. I'm the State Coordinator for Family
3 Voices New Jersey. I'm also a guest on the New
4 Jersey American Academy of Pediatrics, Council
5 for Children with Disabilities, a family
6 stakeholder. And I have no disclosures.

7 DR. WILSON: Thank you, Lauren.

8 And, Marlene, are you with us on the
9 phone as well this morning?

10 MEMBER MILLER: Yes. This is Marlene
11 Miller. I am chief quality officer for
12 Pediatrics at Johns Hopkins Medicine. And I have
13 no disclosures.

14 DR. WILSON: Thank you very much.

15 And I'll just mention that we have two
16 additional Committee members who will be joining
17 us tomorrow, so we'll do their disclosures then.

18 And just a couple of remaining
19 comments. First of all, at any time during the
20 meeting, if you think you have a conflict, you
21 can speak up in real time, you can approach the
22 co-chairs, you can approach any of the NQF staff,

1 and we'll introduce ourselves in a minute.

2 Also, if you think someone else has a
3 conflict of interest, please don't hesitate to
4 speak up. We don't want you to sit in silence
5 and wonder. It is better to ask the question and
6 have us resolve the issue as we are moving
7 through these different measures.

8 So, at this point, do you have any
9 questions on the disclosures or any other
10 information?

11 (No audible response.)

12 DR. WILSON: Okay. At this time, I
13 think, I'll turn it over to the NQF staff to
14 introduce themselves.

15 And, Helen, if you'd like to start?

16 DR. BURSTIN: My pleasure. Hi. I'm
17 Helen Burstin. I'm the chief scientific officer
18 here at NQF. Nice to see so many familiar faces
19 around the table. Always nice when people want
20 to come back for another round.

21 I think this is probably Jeff's third
22 or fourth round at this rodeo, but really

1 appreciate all your help. We know this is a lot
2 of work, but really important work, and we're
3 delighted to have you here.

4 MS. MUNTHALI: Hello. My name is
5 Elisa Munthali. I'm Vice President for Quality
6 Measurement at NQF. Welcome.

7 MS. CHAVEZ: Good morning. Severa
8 Chavez, and I'm the analyst for this project.
9 Welcome.

10 MS. ALLEN: Hi. I'm Nadine Allen.
11 I'm the project manager for this project.

12 DR. WILSON: Suzanne.

13 MS. THEBERGE: Good morning, everyone.
14 This is Suzanne Theberge, the senior project
15 manager on the team. I apologize that I'm not
16 there in person with you all today, very sorry
17 not to be there, but I had a family emergency
18 that prevented me from attending.

19 DR. WILSON: Okay. Before we get
20 started, and I turn it over to the co-chairs,
21 Nadine has a few housekeeping things to go
22 through.

1 MS. ALLEN: So the first most
2 important thing, the restroom. The restrooms are
3 located out here on the right. There should be
4 someone that's sitting at the front desk. They
5 can assist you if you need anything.

6 If you need to make a phone call,
7 there's a quiet area that you can also use. You
8 can also ask that person that's at the front
9 desk, her name is Jennifer Green, and she will be
10 able to assist you.

11 We have three dedicated breaks today.
12 One at 10:30, lunch will be served, provided by
13 NQF, at 12:15, we also have another break at
14 3:30.

15 Laptops and cell phones. We have Wi-
16 Fi. The username is guest, and the password is
17 NQFguest. Please mute your cell phones during
18 the call. Please do not put us on hold. We tend
19 to hear music during the Committee discussion.

20 Also, some additional items. We have
21 -- if you're -- if you need to speak, please use
22 your tent cards. Once you raise your tent cards

1 in the upright position, the chairs will call on
2 you to speak at that time.

3 Also, we have dinner tonight at 6:30
4 at Mio, a contemporary Latin-American restaurant,
5 and that's around the corner from us.

6 CO-CHAIR SUSMAN: All right. Well,
7 again, welcome, everybody. We're going to do
8 this first measure with a little bit more
9 commentary, perhaps, than we would initially
10 think, but only to get us into a good pattern of
11 getting this off to a good start.

12 It really is a very stylized process.
13 There's a lot of rules of the road, if you will,
14 and the NQF staff are tremendous about making
15 sure we sort of stay in the roadway.

16 If there is an opportunity to discuss
17 an issue that becomes particularly thorny, at
18 some point, as co-chairs, we may step in and say,
19 "Okay, we've heard -- anybody got additional new
20 ideas here, we want to keep the process going,"
21 because as you see, we have quite a number of
22 measures to get through.

1 The good news is if I look at the
2 agenda, I think, we've saved at least 20 minutes
3 already, so we better stop while we're ahead. I
4 think, there are flights out this afternoon.

5 At each of the measures, we're going
6 to first allow the measure developer to provide a
7 brief, meaning three to five-minute overview.

8 And I'd ask for this first measure, which is the
9 Pediatric Psychosis: Timely Inpatient Psychiatric
10 Consultation, Number 2805, for those of you who
11 are following your NQF bibles here.

12 If the -- first of all, any
13 disclosures to make?

14 (No audible response.)

15 CO-CHAIR SUSMAN: Hearing none -- oh,
16 yes, okay, please. Thank you.

17 MEMBER SCHIFF: I'll recuse myself.

18 CO-CHAIR SUSMAN: Thank you.

19 I'd ask if the developer for this
20 measure, Rita Mangione-Smith or Naomi Bardach,
21 are available.

22 CO-CHAIR BROOKEY: Should we briefly

1 go over the elements that we'll be voting on, so
2 we know?

3 CO-CHAIR SUSMAN: Yes, that'd be
4 great.

5 CO-CHAIR BROOKEY: Okay.

6 CO-CHAIR SUSMAN: While they're
7 getting set up, we have some entertainment here.
8 And this is just going to briefly review the
9 elements that we have and how we're going to go
10 about on this voting with your nice little
11 clickers, which they'll describe when we get to
12 that point.

13 DR. NISHIMI: So the developers will
14 introduce their measures in two to three minutes,
15 and then we will begin walking through the
16 evaluation. Each measure has a lead discussant
17 that we're asking to introduce the measure,
18 discuss the strengths, and the weaknesses first
19 on the evidence because that's the first thing
20 that's up, and then we'll vote on evidence.

21 Evidences must pass. If it fails on
22 evidence, then we don't discuss anything further

1 about the measure.

2 Then we move to performance gap. And
3 again, the lead discussants will introduce the
4 measure, and we ask the Committee to join in
5 because all of you, of course, we're asked to
6 look at every measure, and then we'll vote on
7 performance gap.

8 Again, must pass. If it doesn't pass
9 gap, then we don't discuss the measure any
10 further.

11 And we proceed that way through both
12 reliability and validity. Both of those are must
13 pass.

14 Usability and use, feasibility are not
15 must pass, but we still vote after we discuss
16 those criteria. And then there's a final vote on
17 the overall suitability for endorsement.

18 So you have clickers, and when the
19 time comes, we'll do a test vote, and then we'll
20 vote for real.

21 Go to the next slide. I just want to
22 say a little bit about how the voting is

1 tabulated. It's automatically tabulated, but to
2 be recommended for any of the single elements,
3 greater than 60 percent of the Committee must
4 approve it.

5 If it's between 40 and 60 percent vote
6 on that criterion, or on the overall suitability
7 for endorsement, NQF refers to that as consensus
8 not reached. So we proceed with the evaluation,
9 we proceed with the discussion, but there's a
10 designation consensus not reached.

11 And what happens there is the measure
12 goes out for public comment, we'll get comments
13 or not, the developer may bring forward
14 additional information, and then when you have
15 the follow-up call after the comment period
16 closes, we would ask you to then vote, re-vote on
17 that, and you may still not reach consensus, but
18 at least you will have, hopefully, received
19 additional information.

20 If there is less than 40 percent, so
21 39.9 or lower, then the criterion fails or the
22 overall measure fails.

1 Any questions about how that goes
2 down?

3 (No audible response.)

4 DR. NISHIMI: We will alter things
5 slightly when we get to the FECC measures, the
6 FECC measures, because we're going to take those
7 up in, all ten at once on evidence, all ten at
8 once at its gap, etc., because a lot of the
9 discussion will be the same. There was
10 overlapping discussion. So when we get to that,
11 we'll make it clear how you're voting there.

12 Okay. Great.

13 CO-CHAIR SUSMAN: All right. Now, I
14 hope everybody is ready to listen to our measure
15 developers. Thank you for attending today.

16 DR. BARDACH: Thank you very much.
17 I'm Naomi Bardach. I'm at UCSF, the University
18 of California San Francisco, and I'm part of the
19 Seattle Center of Excellence this morning.

20 You'll be discussing three measures
21 today that we're presenting on pediatric mental
22 health in the ED or inpatient setting. The

1 measures are submitted by the Center of
2 Excellence on Quality of Care for Children with
3 Complex Needs, which is housed at Seattle
4 Children's Research Institute.

5 The process for developing these
6 measures was the same, so I'm only going to
7 review it once. The Center's Mental Health
8 Working Group after developing a conceptual
9 framework for the measures determined the most
10 common reasons for pediatric mental health
11 presentations to the ED or inpatient setting
12 nationally.

13 And then we performed literature
14 reviews for the top conditions. The lit reviews
15 inform the content of the measures. We then
16 presented the measures to a multi-stakeholder
17 Delphi panel, which included caregivers of
18 children with mental health problems, also mental
19 health and pediatric clinical specialists, and
20 Medicaid health plan representatives.

21 Measures that met Delphi panel faced
22 validity criteria were then operationalized and

1 field tested. We submitted for endorsement only
2 those measures that performed well throughout
3 these processes.

4 The measure currently under
5 discussions, the medical record-based measure of
6 the percentage of patients. It's called,
7 "Pediatric Psychosis, 2805," just to orient you
8 guys, "Timely Inpatient Psychiatric
9 Consultation." It's a medical record-based
10 measure of the percentage of patients age 5
11 through 19 who were admitted to the hospital for
12 psychosis who had a psychiatric consult, in
13 person or by telepsychiatry, within 24 hours of
14 their admission.

15 There's just a few specific responses
16 to questions that came up in the workgroup call
17 that we wanted to review. Overall, we would like
18 to acknowledge the dearth of evidence regarding
19 the delivery of mental health services to
20 children.

21 There are a couple of very important
22 points to be made. First of all, the populations

1 are often hard to study since they and their
2 families are extremely vulnerable during acute ED
3 and inpatient episodes, and the presentation is
4 relatively rare compared to something, such as
5 adult acute MI.

6 If the Committee supports waiting for
7 more robust evidence in order to endorse measures
8 for accountability, it may be quite a long time
9 before we are able to measure performance for
10 these important groups of children.

11 We know from work also done in
12 preparation of measure development that there are
13 very few existing pediatric mental health
14 measures despite nine percent of pediatric
15 hospitalizations nationally for ages three and up
16 being for mental health conditions.

17 Given the dearth of data and the
18 numerous barriers to creating strong evidence to
19 support quality measure development for the
20 children, we believe these measures would most
21 appropriately be considered under the evidence
22 criteria of insufficient with exception.

1 Just one other thing specifically for
2 this measure, 2805, there is one update, a study
3 published earlier this year of pediatric patients
4 in a tertiary care hospital who received a
5 psychiatric consultation. The study found that a
6 ten percent decrease in time to consultation was
7 associated with an eight percent shorter length
8 of stay, which was statistically significant, and
9 a similar magnitude decrease in cost.

10 This study just adds to our measure
11 validation work that found a decrease length of
12 stay for those patients who passed the measure.

13 Given a limited time for this
14 instruction, clock is ticking, I will only
15 comment that we do have further information
16 regarding three specific additional workgroup
17 concerns, which were first of all the age range
18 for the measure, secondly, a concern regarding
19 allowing a pass for consultation performed up to
20 48 hours if the provider documented a
21 justification in the chart, and lastly, there was
22 a concern about a somehow high pass rate in our

1 field testing.

2 I'm happy to provide additional
3 information on any of those issues when asked
4 before going to the map.

5 CO-CHAIR SUSMAN: I've just been told
6 that Virginia Moyer just arrived, so we need to
7 go through a disclosure.

8 Maybe you'd like to introduce yourself
9 first. And please use your microphone.

10 DR. WILSON: It's the button on the
11 right.

12 MEMBER MOYER: I pushed it. It just
13 didn't do anything.

14 DR. WILSON: It's on now.

15 MEMBER MOYER: I'm Ginny Moyer. I'm
16 the vice president for MOC and Quality at the
17 American Board of Pediatrics. And for today's
18 meeting, I am going to recuse myself from four
19 measures because of involvement with the
20 committees that produced those measures, 2799,
21 2800, 2801, and 2803.

22 DR. WILSON: Great. Thank you very

1 much.

2 CO-CHAIR SUSMAN: Thank you for that
3 brief interruption.

4 Anything to add?

5 (No audible response.)

6 CO-CHAIR SUSMAN: Okay, great. Well,
7 that was a good example of keeping it short,
8 sweet, and to the point. I appreciate it.

9 So let's go ahead and we'll first have
10 a little bit of description, so the lead
11 discussant will go through, again, the measure.
12 Try to give an overview of what the analysis is,
13 the level of analysis, what's the denominator,
14 numerator, and then to launch off into the
15 evidence.

16 So it looks like that's Dr. Keller,
17 Dr. Bristol-Rouse, and Dr. Moyer.

18 Who's the lead discussant on this one?

19 MEMBER KELLER: Well, if that means
20 whose name was first, I think, that was mine.

21 CO-CHAIR SUSMAN: Okay. Well, why
22 don't you start us off?

1 MEMBER KELLER: That actually wasn't
2 entirely clear to me, and this is my first
3 meeting, so I was being a little hesitant.

4 The -- so the measure is a pretty
5 straightforward one. As we've already heard, it
6 was the percentage of children and adolescents,
7 age greater than or equal five and less than or
8 equal to 19, admitted to the hospital with
9 psychotic symptoms who had a psychiatric consult
10 in person or by telepsychiatry within 24 hours of
11 admission.

12 I think, during our discussion, the
13 issue of how to identify psychotic symptoms
14 versus diagnosis of psychosis was raised, and --
15 but during the test phase and validation, they --
16 measure developers had addressed that as, in the
17 process of being able to obtain that data out of
18 the electronic health record in a systematic
19 fashion from the three institutions they worked
20 with for that.

21 The other issue was about the -- that
22 was raised during our discussion was really how

1 to define a psychiatric consultation and whether
2 there were times or reasons where the 24-hour
3 limit would not be met just because of arbitrary
4 workflow processes within the hospital that the
5 evidence for picking 24 hours is the standard was
6 not very clear to us in going through, in going
7 through that measure.

8 The measure was based on guidelines
9 that have been developed from what evidence there
10 is. As we heard from the introduction, there is
11 not a lot of evidence to go on here, but this is
12 -- so a lot of what was done is based on
13 consensus of experts given that, I think,
14 everyone felt it was a reasonable thing to look
15 at.

16 The -- per the algorithm for evidence,
17 we all thought that the, that this probably did
18 qualify, as was mentioned in the introduction, as
19 an exception, where we didn't have a lot of
20 evidence but that we thought this was important
21 measure and we were hard-pressed to come up with
22 something that was a negative that would come out

1 of using this as a standard that people would
2 work towards.

3 The -- there was concerns raised
4 because the three hospitals that were used are
5 fairly advanced hospitals with well-developed QI
6 processes and electronic health records that are
7 -- we were wondering how well this measure would
8 be applied in other kinds of hospitals,
9 particularly in general hospitals that were not
10 pediatric-specific.

11 And the -- and the concern about
12 having to do -- that the chart auditing process
13 would make it infeasible to actually bring this
14 measure out into wider distribution. We were
15 also concerned that at, again, hospitals that
16 don't have large numbers of children that the N
17 for the denominator would be relatively small,
18 and therefore, would be subject to a lot of
19 variability.

20 As far as usability and use, this is a
21 new measure, and so is not currently in use
22 anywhere, so we had no real way to judge how well

1 it's being used because it hasn't been used yet,
2 but there were no concerns raised about
3 unattended consequences.

4 Anything else I'm forgetting from that
5 conversation? I'm looking at my fellow leads.

6 MEMBER MOYER: The only issue is that
7 I'm not remembering well information from the
8 developer about the definition of the
9 denominator. As it reads, it's those who are
10 discharged, with a discharge diagnosis of
11 psychosis. It's not those who are admitted with
12 psychotic symptoms.

13 MEMBER KELLER: Thank you. Sorry.

14 MEMBER MOYER: And so, I'm just
15 interested from the --

16 MEMBER KELLER: I wasn't clear on
17 that. There was -- there was some concern about
18 that definition expressed.

19 DR. BARDACH: So to clarify, that's
20 correct. It's based on the discharge diagnosis,
21 and the denominator population eligible patients
22 are identified using the administrative data, so,

1 yes, it would be a discharge diagnosis rather
2 than an admission.

3 MEMBER MOYER: So was any work done to
4 determine whether there were patients who were
5 admitted with psychotic symptoms, but not
6 discharged with a diagnosis of psychosis? And
7 based on our group discussion, that was one of
8 the primary concerns that, particularly younger
9 kids with psychotic symptoms, usually are
10 actually -- do not have psychosis as a diagnosis
11 at the time they go home.

12 DR. BARDACH: So in the development
13 work because we used the ICD-9 codes
14 administrative of record to identify the eligible
15 population, there was no assessment of kids who
16 came in with the symptoms of psychosis who did
17 not have a discharge diagnosis.

18 CO-CHAIR SUSMAN: Okay. So one of the
19 first questions we're going to have in each of
20 the measures we consider is whether this is a
21 process or outcome measure. And I assume that
22 this is a process measure that there is no link

1 directly to the outcome.

2 And that also brings us to the
3 question of the evidence here as the measure
4 developers noted. There really isn't a body of
5 evidence, or certainly it's a very early body of
6 evidence linking this to some patient-oriented
7 outcome that would be of interest.

8 If you -- remember this wonderful
9 table? It gives us some guidance around the
10 ratings of evidence. And in this case, the
11 evidence is lacking. You know, there isn't even
12 moderate evidence as defined here, which, does
13 the grade of evidence indicate high quality
14 evidence, is it high grade, high quality?
15 Answer, no, no grading of evidence, no summary,
16 not graded or strong recommendation.

17 Is there empirical evidence without
18 systematic review and grading of the evidence?
19 That's box seven on our algorithm and going down
20 through that.

21 I think, at best, does the empirical
22 evidence that it summarize include all studies in

1 the body of evidence? Well, there's really not
2 much evidence to even include here.

3 So we either are getting too low, or
4 on your page here, since there wasn't any
5 systematic review and there's not much evidence
6 to review, we're going to get to a series of
7 conditions that have to be met for an exception,
8 which is, I think, what you all have been
9 recommending as the primary reviewers.

10 And in box ten, it says, "Are there,
11 or could there be, performance measures of a
12 related health outcome, or evidence-based
13 intermediate clinical processor outcome?" And if
14 the answer is no, to see is there evidence of
15 systematic assessment of expert opinion and
16 consensus recommendation, benefits of what is
17 being measures outright risk. And in this case,
18 there was a formal Delphi method that came up
19 with a consensus around this is a relatively
20 strong measure.

21 And then it goes down to 12, does the
22 Steering Committee agree that it's okay or

1 beneficial to hold providers accountable? So
2 remember, this is not just for performance
3 improvement, but it's accountability, and we
4 don't control how these measures are being used.

5 So at least in my mind when we talk
6 about accountability of providers, we want to
7 make sure there's a certain amount of rigor, or
8 if there isn't and we're recommending an
9 exception that we do that knowing that people may
10 be held accountable in some health plans or other
11 measurement environments. And it goes on to
12 describe then how that might be in the absence of
13 empirical evidence.

14 So again, I invite comments from those
15 of you who more closely looked at this, but at
16 least that's how I make the evidence rating of
17 this boiling down to probably an insufficient
18 evidence with an exception.

19 Please.

20 MEMBER MORROW-GORTON: As part of our
21 discussion, I think, we -- it was not entirely
22 clear that the population of kids that you were

1 looking at were only those kids with a diagnosis
2 of a psychotic disorder. And given that, there
3 are -- is the potential for, and we have no idea
4 what the volume of those children are, for
5 children to have presented with psychotic
6 symptoms in the ED and for it to have been an
7 entirely different reason, and asking hospitals
8 and professionals to do child psych consultations
9 for, for all of those children when we don't know
10 whether there's any benefit or harm to them by
11 having a child psych evaluation at presentation.

12 I think, it's a little concerning in
13 that we don't know what the volume of that group
14 of children is. We don't know what the age
15 distribution is. The younger children are much
16 less likely to have psychotic disorders, and in
17 many of these situations, child psych consult may
18 not be helpful.

19 CO-CHAIR SUSMAN: Kevin.

20 MEMBER SLAVIN: One of my questions
21 around this really has to do with the
22 accountability part, and that is, especially when

1 you start getting into the younger children, the
2 dearth of available psychiatric consultations,
3 whether in-person or by telemedicine, especially
4 as you start getting into more remote areas or
5 areas where there are not strong tertiary
6 centers, and so to hold accountable to a metric
7 when the services are not accessible raises some
8 concern in my mind.

9 CO-CHAIR SUSMAN: Other questions or
10 comments?

11 Yes, Ricardo.

12 DR. NISHIMI: Just when you -- when
13 you want to talk --

14 MEMBER QUINONEZ: Oh, I'm sorry.
15 Okay. Right, I got it.

16 CO-CHAIR SUSMAN: Go for it.

17 MEMBER QUINONEZ: Yes. So I -- just
18 to follow on that last point. I think, sometimes
19 the, the reasons for measures is to, is to --
20 it's to encourage those processes being
21 developed. I mean, I think, we would all agree
22 that the lack of psychiatric consultation in

1 different areas of the country is a problem, and
2 until somebody is held accountable for that, it's
3 not going to change.

4 CO-CHAIR SUSMAN: There is a, if you
5 will, put a measure out there, it moves out
6 systems and the dynamics of our healthcare
7 organizations for sure.

8 Other comments or questions?

9 MEMBER MILLER: This is Marlene.

10 CO-CHAIR SUSMAN: Go ahead.

11 MEMBER MILLER: Hello? Oh, yes,
12 sorry. You know, I just think, on that last
13 comment, I think, the goal of measure should be
14 that there is evidence that may matter more so
15 than using a measure to move policy or change
16 systems because that accountability piece has
17 important ramifications of where resources -- a
18 lot of measurement resources get put, so I do
19 think -- on many, many of these measures, we
20 straddle what we think we should want in the
21 ideal world versus what -- is there actually
22 evidence that the thing being measured matters.

1 And I believe our focus here has to be
2 a little bit more heavy on where the evidence is
3 the actual measure and effects matter.

4 CO-CHAIR SUSMAN: Thank you.

5 And I can't see whose it is.

6 MEMBER HOUTROW: It's Amy Houtrow.
7 Hi.

8 CO-CHAIR SUSMAN: Okay, thanks.

9 MEMBER HOUTROW: I have two points.
10 The first point is that in many adult hospitals
11 in which teenagers would present, they might not
12 never see a psychiatrist either my telemedicine
13 or otherwise. They might see a social worker and
14 be on a medical hold until they're placed, and
15 that would be at a completely appropriate pathway
16 to getting treatment.

17 The second point is there might be
18 many times when psychosis would show up on a
19 discharge diagnosis that's unrelated to the, the
20 reason the child was admitted. So for example,
21 if you're in a car crash and you have a severe
22 traumatic injury, you might emerge from your coma

1 into a state of psychosis for which you could
2 then be discharged to a rehab facility, which
3 would be a completely appropriate pathway for
4 your treatment that would be completely outside
5 of a psychiatric pathway, and so, therefore, you
6 could end up with a psychosis discharge
7 diagnosis, but being the scenario, a clinical
8 scenario, which is kind of underlying not a
9 psychiatric problem.

10 CO-CHAIR SUSMAN: Okay. Very good.

11 Why don't we just go down the line
12 here?

13 MEMBER BRISTOL-ROUSE: I know the
14 developers mentioned that part of the group that
15 -- you put together the measures included family
16 members and so on. I'm curious since there is
17 this lack of evidence, you know, how many family
18 members were part of this and what were their
19 kind of thoughts on the importance of this since
20 some of our discussion here today is whether it's
21 going to matter to the children themselves.

22 CO-CHAIR SUSMAN: So what I'd ask we

1 do is if there are questions for the developer,
2 why don't we try to put those all out there, and
3 then we'll get a very brief comment answers if
4 you have them. And then I'm just going to go
5 down this side beginning with Kerri.

6 I'll get back to you, John.

7 MEMBER FEI: Thinking of this from a
8 health plan perspective regarding the evidence,
9 if me at a health plan is going to hold providers
10 accountable for this measure, we have to be sure
11 that it's based on pretty good evidence. And I
12 know that is a struggle from developing pediatric
13 performance measures, I know that is a struggle,
14 and then sometimes we have to put measures out
15 there.

16 However, if I'm going to either in
17 sense or take away money from providers based on
18 this measure, it needs to be based on strong
19 evidence.

20 CO-CHAIR SUSMAN: And just to clarify
21 the task at hand NQF staff, please keep me
22 straight, we're going to be voting on the level

1 of evidence. If it turns out to be insufficient,
2 then we'd have to separately vote whether there's
3 an exception or not, so as you're thinking about
4 the task at hand. That correct?

5 MS. MUNTHALI: Yes.

6 CO-CHAIR SUSMAN: Okay. So let's go
7 down, and I can't see whose sign that is if it's
8 -- David.

9 MS. MUNTHALI: You need to hit your
10 mic.

11 MEMBER KELLER: Oh, sorry.

12 One of the things that's interesting
13 to me is that for the three sites that, for this,
14 which this measure was tested that the rates of
15 positive, the rates of compliance were actually
16 pretty high at all three sites. We didn't find a
17 lot of, as much evidence and variation as I would
18 have thought.

19 And that sort of speaks to your point,
20 I think, a little, a little bit. What I'm
21 wondering about is whether at smaller hospitals -
22 - whether at smaller hospitals, you would see

1 more variation than you did at these large
2 hospitals.

3 And certainly, where we too say going
4 ahead here, I think, we need to look very
5 carefully at the implications for this for
6 general hospitals and hospitals without a
7 pediatric focus because, I think, that you might
8 find something different.

9 But I did think there was evidence
10 that this is standard of care for at least at
11 large children's hospitals, and that's something
12 that we should keep in mind as we're thinking
13 about whether or not that's generalizably
14 possible across the nation.

15 CO-CHAIR SUSMAN: Okay. David.

16 MEMBER EINZIG: So I just want to
17 preface this with, I really like the idea of the
18 measure, but in terms of evidence, the question
19 of should it be a psychiatrist who does the
20 consult and is the evidence to say that a
21 psychiatrist does a better job than a
22 psychologist in terms of a psychologic

1 assessment.

2 I think, in terms of -- so the reason
3 why a person will be held in a pediatric hospital
4 is primarily for safety while they're waiting to
5 be housed to get to a more appropriate setting, a
6 psychiatric unit or whatever the next appropriate
7 level of care is.

8 So this might be jumping the gun into
9 feasibility, but just in terms of -- keep it --
10 focus on evidence -- is there -- is there
11 evidence to say that a psychiatrist does provide
12 a better, do a better job than a psychologist or
13 other provider in terms of doing that assessment?

14 CO-CHAIR SUSMAN: I'm going to go
15 ahead and take Jon and Virginia, and then we'll
16 get some comment from our developers. And Jon
17 had a question of the developer, so -- Jon, over
18 here.

19 MEMBER FINKELSTEIN: So I too am --
20 I'm positively disposed to the measure. I think,
21 most children come in with psychotic symptoms in
22 the ED need a pathway to quick mental health

1 consultation and care.

2 Some of the discussion to me speaks to
3 what would be exclusions where the measure in
4 particular cases didn't quite make sense. And
5 we'll be considering other measures based
6 completely on claims where those exclusions will
7 be opaque to us in the measurement process, but
8 in this case where you're actually looking in the
9 chart, I wonder if the developers thought about
10 exclusions that you could also get from the
11 chart, the rare event where psychosis, these
12 symptoms weren't present on admission, but
13 developed in the course of a hospitalization,
14 Amy's case, or other, other reasons why the
15 measure wouldn't make sense.

16 If it's a very large N measure, these
17 very rare exclusions might not matter, but
18 especially in smaller institutions where the N
19 itself might be very small, one or two cases
20 where there actually was a rational reason for
21 delay or a different pathway might make a big
22 difference.

1 CO-CHAIR SUSMAN: Thanks. Good
2 points.

3 Virginia.

4 MEMBER MOYER: So I have actually
5 another question for the, for the developers.
6 The paper that was distributed after the pre-
7 meeting does show an association, I'm not clear
8 whether it's causal or not, but it does show an
9 association between the length of hospital stay
10 and the timing of the initial psychiatric
11 consult.

12 I would just like to hear a little bit
13 more about the -- what the expected benefit of
14 this measure is, other than shortening hospital
15 stay where we really don't have particularly
16 strong evidence. We have a piece of evidence,
17 but we don't have a lot of evidence beyond
18 shortening of hospital stay.

19 What are the other benefits that we
20 think would accrue for an earlier psych consult?
21 And, I also just want to comment that I also have
22 a concern that it specified that it's a

1 psychiatric consult when perhaps a mental health
2 professional consultation would be what you are
3 really looking for.

4 My third concern is, I think, I've
5 already expressed, is that the kids I'm worried
6 about -- I like the idea of the measure also
7 because the kids I'm worried about are the ones
8 who need early evaluation, and that's not what
9 we're finding. The denominator is not those
10 kids. The denominator is the kids who've had a
11 later diagnosis.

12 CO-CHAIR SUSMAN: Okay.

13 Maureen, do you have a comment?

14 MEMBER MILLER: Marlene you mean?

15 CO-CHAIR SUSMAN: Yes.

16 MEMBER MILLER: Okay.

17 CO-CHAIR SUSMAN: I'm sorry.

18 MEMBER MILLER: It's okay. I get
19 called that all the time; that's why I still
20 reply.

21 CO-CHAIR SUSMAN: Yes. I need to see
22 your name tag. That's the problem.

1 MEMBER MILLER: No problem.

2 So, yes, I wanted to go back to that
3 comment about the three half of this was tested
4 and had fairly high, if not standard of care
5 already performance on this, and, I think that's
6 a very valid point. We have a history in some of
7 the pediatric measures, and for those of you that
8 know -- for example -- the Joint Commission as a
9 measures, that was exactly the conversation, the
10 measures were very high in children's hospitals,
11 the performance was high already, but maybe at
12 small hospitals it wouldn't be.

13 And we went down this ten-year path of
14 many, many resources being poured into measuring
15 this, which finally -- finally this year -- is
16 being retired by the Joint Commission because it
17 had no evidence of any impact, and so I do -- you
18 know, I think we have to think about that.

19 You know, it doesn't mean that this
20 measure is not acceptable, but it would really
21 need to be proven to me, I think, that there is a
22 performance gap because the data that was given

1 showed very, very high performance at children's
2 hospitals. We don't want to make measures where
3 everyone's, you know, 95 percent already.

4 CO-CHAIR SUSMAN: So, I've heard from
5 the group some concerns about the tie to the
6 evidence that we shouldn't be holding people
7 accountable for a performance measure that has a
8 dearth of evidence. I've heard some questions
9 about what outcomes are intended to be improved
10 other than length of stay, some technical
11 questions about specification of the measure --
12 for example, why not mental health provider as
13 opposed to a psychiatrist or a psychologist being
14 an appropriate way.

15 And, then I'm going to put on the
16 parking lot for just a moment the questions about
17 gap, which we get to vote on, I believe,
18 separately here. So, let me turn it over to our
19 measure developers to briefly respond to any --

20 DR. MANGIONE-SMITH: Thanks for all
21 your thoughtful analysis of the measure, and I'll
22 try to make sure that we address all of the

1 different concerns that have been raised.

2 The first one I'll take up is the
3 issue of a young child presenting in the ED with
4 psychotic symptoms who is not actually a child
5 who has psychosis and inappropriately applying
6 this measure to that sort of child.

7 So, when we went from the language of
8 the draft's quality measure to operationalization
9 of that measure, the choice was made to identify
10 these cases using administrative data with a list
11 of ICD-9 codes that were vetted by our mental
12 health working group. So, we are talking about
13 retrospectively looking at cases where there was
14 a clear diagnosis of psychosis.

15 So, the measure is not -- the
16 denominator does not include children who just
17 present to the ED with psychotic symptoms and
18 don't end up leaving an inpatient stay with a
19 diagnosis of psychosis.

20 In terms of the concern about, is that
21 a valid diagnosis? The first step in our medical
22 record abstraction tool that the abstractors are

1 asked to do is to verify that, in fact, this
2 child was diagnosed with psychosis in this
3 admission, but either by their discharge summary
4 or any other parts of the chart that the
5 abstractor has access to.

6 The next thing I wanted to address
7 that's come up multiple times is the need for
8 this to be done by a psychiatrist. And I'd like
9 Naomi to read to you the directions that are
10 given to the abstractor about what counts as a
11 psychiatric consult.

12 DR. BARDACH: So, the instructions
13 are, "The consult may be in person or by
14 telemedicine. The consult must have been done by
15 a psychiatrist or a PhD psychologist. If the
16 consult was done by a clinician extender, nurse
17 practitioner, advanced practice nurse, physician
18 assistant, licensed social worker, or licensed
19 counselor, this is acceptable as long as the
20 assessment is co-signed by a psychiatrist."

21 DR. MANGIONE-SMITH: Okay. So, it's
22 not just a psychiatrist. It can be a PhD

1 psychologist that doesn't even require a co-
2 signature, but if it's an extender, we do require
3 that there be a signature by a psychiatrist, a
4 co-signature.

5 In terms of what was our family
6 representation and development of the measures in
7 considering the measures, Carolyn Allshouse --
8 who is the lead person for Family Voices of
9 Minnesota -- is a member of our Center. She put
10 together a panel of ten parents who advised on
11 the development and all stages of our measures.

12 They had review of our lit reviews,
13 they reviewed all the draft measures, they gave
14 us feedback, so even before the measures hit our
15 Delphi panel, we had a really rich amount of
16 parent input throughout the process. And, then
17 on the Delphi panel, Lynn Pedraza -- of Family
18 Voices -- was a member of our Delphi panel that
19 assessed the final mental health measures.

20 An issue that was brought up with
21 regards to this only being tested in three
22 children's hospitals, we did have two community

1 hospitals in Minnesota, which we would have loved
2 to include -- before this measure, they are
3 included in the other -- one of the other
4 measures that we'll be discussing today. They
5 don't have inpatient units for children, and when
6 they have a child present to the ED with
7 psychosis, they send them to a tertiary care
8 center or a center that does have an inpatient
9 psychiatric unit for children.

10 I think most inpatient -- and I don't
11 have data to support this right now -- but I
12 would imagine most psychiatric inpatient stays
13 for children are likely not going to be happening
14 in general adult psychiatric units. I imagine
15 it's possible, but I would think it would be
16 rather rare.

17 So, I think these children will be
18 clustered in tertiary care centers or in actual
19 psych facilities. Whether we would see more
20 variation and gap in performance if this were put
21 in a more widely distributed swath of hospitals
22 remains a question unanswered, and that to me

1 would be part of stewardship of this measure.

2 It would be very important for us to
3 continue to track performance and understand
4 whether there's no variability because if there
5 is no variability and it's a capped out measure,
6 I agree it's not a very useful measure for
7 accountability purposes.

8 Did you have anything you wanted to
9 add? And, I --

10 CO-CHAIR SUSMAN: Any -- any comments
11 further about what the anticipated improvement in
12 patient oriented outcomes would be?

13 DR. MANGIONE-SMITH: Oh, yes. Right.
14 So, that was -- that was actually a key driver
15 for this measure. It was not just trying to
16 decrease length of stay or costs. Unfortunately,
17 that's the only thing that the literature has
18 focused on.

19 Our concern in thinking through this
20 measure -- and you're going to be hearing about
21 many more measures in this two-day period about
22 the misuse of anti-psychotic medications in young

1 children --- there's concern on our part that
2 anti-psychotics get started without a legitimate
3 evaluation of whether a child actually needs to
4 be on an anti-psychotic medication.

5 So, one of the hopeful outcomes of a
6 measure like this would be that the
7 appropriateness of treatment with anti-psychotics
8 would improve. The other piece that we know is a
9 problem is continued return to the emergency
10 department with these types of symptoms and re-
11 hospitalizations, so the hope is that if a
12 psychiatrist were to become involved earlier on
13 that appropriate follow-up care in the outpatient
14 setting would be more likely to occur.

15 CO-CHAIR SUSMAN: Okay. Thank you to
16 our developers.

17 And Kevin, you had a comment.

18 MEMBER SLAVIN: Sorry, I don't want to
19 sort of keep on this, but there were -- I think,
20 getting back to Dr. Moyer's comment about the
21 younger children in particular, one of the
22 problems with -- that I sort of foresee is that

1 sometimes a measure drives an action that is
2 unintended.

3 So, in this case, even though it's a
4 retrospective look-back on patients who were
5 discharged with a diagnosis of psychosis, if a
6 young child or even a teenager comes in with
7 acute psychosis with no prior history of
8 psychosis, the medical evaluation is often not
9 completed within the first 24 hours.

10 But with the measure looking back and
11 saying -- let's say this person does end up
12 having psychosis as one of their discharge
13 diagnoses, it might drive a psychiatric
14 evaluation for those that were not captured in
15 the data set when a psychiatric evaluation was
16 not needed. And that's sort of one concern in
17 terms of driving use of resources and use of
18 psychiatrists.

19 Two other things I kind of wanted to
20 mention. One is the supplemental study that was
21 added or that was mentioned after the fact, when
22 looking at that study a lot more closely, only 5

1 percent of the patients actually had a diagnosis
2 of psychosis, so the shortened length of stay was
3 actually based on about 80 percent of patients
4 whose final diagnoses were anxiety, depressive
5 disorders, or some out of form disorders, which I
6 anticipate to be shorter term hospitalizations as
7 well, and so I don't know if that actually adds
8 to the data driving the evidence for this, and I
9 was wondering if there are any comments about
10 that.

11 And, then one question about the
12 abstraction tool. The -- I noted the list of
13 extenders didn't include residents, and I wasn't
14 sure if residents actually fell into that list as
15 well. Like a psychiatric resident might evaluate
16 a patient, but the psychiatrist might not sign
17 off on it until after. I didn't know if they
18 were included in that list of the abstract-able
19 consultations.

20 CO-CHAIR SUSMAN: So, why don't we
21 have the results.

22 DR. BARDACH: So, I'll start, and then

1 Rita Mangione-Smith might have some more things
2 to add.

3 Just a couple things about the age
4 group. So, we did look at the distribution of
5 ages in the eligible patients. There's a very
6 small number of kids who are younger than the age
7 of ten.

8 It was only five percent of our -- of
9 the eligible population in the field testing.
10 So, just to reassure the crowd about the younger
11 age groups, it's just not very many were actually
12 eligible for it.

13 MEMBER SLAVIN: Were those patients
14 who were discharged with a diagnosis of
15 psychosis?

16 DR. BARDACH: Discharged with it, yes.

17 MEMBER SLAVIN: So, I think, the
18 concern is the ones that don't get discharged
19 with a diagnosis of psychosis because maybe they
20 present with encephalitis or some other medical
21 condition.

22 DR. MANGIONE-SMITH: One other thing

1 that we have discussed as a center since the
2 initial workgroup called because they are such a
3 small fraction of who we even saw show up in the
4 denominator and because of this concern that you
5 might be pushing people to prematurely be doing
6 psychiatric consults in kids who very well may
7 not need them.

8 I don't think that we would have an
9 issue with limiting the age range to the
10 adolescent population for both this measure, and
11 we'll talk about the other one later today. I
12 think that's a reasonable suggestion, and given
13 what we found in the field test is supported by
14 what we found in the field test.

15 CO-CHAIR SUSMAN: And, just remember,
16 we're voting on the measure as presented, and
17 certainly in subsequent work, developers can re-
18 tool their measure, re-target their measure, or
19 what have you.

20 So, David.

21 MEMBER EINZIG: So, I know this is
22 just semantics, but when I read psychiatric, I

1 think psychiatrist. And, I'm sensitive to that
2 because when I got consulted as a psychiatrist by
3 the team, sometimes they really don't want a
4 psychiatrist; sometimes what they're looking for
5 is a psychologist, and so I think the semantics
6 are important there.

7 And, just for clarification, so if
8 it's an LICSW who does that initial consult, that
9 does not count as a psychiatric consult?

10 DR. MANGIONE-SMITH: It would count as
11 long as it were countersigned by either a PhD
12 psychologist or a psychiatrist. So, if there was
13 an evaluation done by a licensed social worker
14 and it was cosigned by either a PhD psychologist
15 or an MD psychiatrist, it would count.

16 MEMBER EINZIG: Yes. And, forgive my
17 ignorance. So when a psychiatrist or a PhD
18 psychologist cosigns, does that imply that they
19 also see the patient or they just review with the
20 --

21 DR. MANGIONE-SMITH: My assumption ---
22 as somebody who cosigns residents' notes all the

1 time and I'm expected to see the patient -- my
2 assumption is they would have already -- they
3 also would have evaluated the patient to some
4 degree.

5 CO-CHAIR SUSMAN: Yes, I think, just
6 my own background, it would seem that there's
7 variability in state regulations of licensure.
8 And, the scope of practice, certainly, there are
9 some states where those individuals are fully
10 licensed to independently evaluate and treat
11 using psychotherapies at least their patients, so
12 that is, I think, an important issue.

13 Okay, I'm seeing our -- I'll get your
14 comment, but I'm seeing we're starting to wind
15 down here, so if we can focus on evidence or
16 critical questions that haven't yet be answered,
17 we can go on to voting on evidence.

18 Ricardo.

19 MEMBER QUINONEZ: I just have a very
20 technical question about the measure. The 24
21 hours, if a child is admitted at a -- comes to
22 the ER to an adult facility and then subsequently

1 gets transferred to the either an inpatient
2 psychiatric facility or a children's hospital --
3 most likely a children's hospital -- where
4 there's a 24-hour start, and where did you come
5 up with the 24 hours? What was the --

6 DR. MANGIONE-SMITH: So, the 24-hour
7 clock starts at the timestamp of admission to the
8 hospital where the child is treated for their
9 psychosis. So, if you were transferred from an
10 adult ER to a children's hospital psych unit, the
11 24 hours starts when you're admitted to the psych
12 unit.

13 And in terms of the 24 hours, it was
14 heavily and strongly debated at our Delphi panel
15 whether that was the right cutoff. We started --
16 that measure was drafted at 48 hours and the
17 mental health people on our Delphi panel felt
18 that that was too lenient and wanted it to be 24
19 hours, but then agreed that it could be 48 hours
20 as long as you provided a justification for why
21 it took 48 hours.

22 So, that is the -- where the 24 hours

1 came from was from the Delphi panel
2 recommendation that it be made more stringent.

3 MEMBER MOYER: Just another question
4 for the developers. So, if the child got the
5 psych consult in the emergency room prior to
6 admission, how is that handled?

7 DR. MANGIONE-SMITH: So, if it's at
8 the index hospital where you're measuring, that
9 counts.

10 MEMBER MOYER: How would you know
11 that? What -- is there -- is there a process by
12 which that would have been determined?

13 DR. MANGIONE-SMITH: So, the chart
14 review, you want to say what it --

15 DR. BARDACH: Yes. Just says,
16 "Include in this interval any psychiatric consult
17 that may have been done in the marker ED prior to
18 admission if the patient was admitted by the
19 marker ED." So, it's just part of the
20 abstraction instructions.

21 CO-CHAIR SUSMAN: Okay. Any final
22 questions?

1 David, is your -- no, okay.

2 Yes, Virginia.

3 MEMBER MOYER: You're probably about
4 to do this, but if you are you can pay me later.
5 I just need to be very clear on what we're
6 looking for now. I'm reading the questions that
7 are in the summary, "Is the evidence directly
8 applicable to the process of care? Is there
9 sufficient evidence of the relationship of this
10 measure to patient outcomes?"

11 And I'm looking at those and wondering
12 if that's what we are about to --

13 CO-CHAIR SUSMAN: Yes. I wonder if
14 the staff might be able to put up the algorithm
15 if possible. If not -- basically, we're dealing
16 with either -- and this is what it looks like.
17 Perhaps you have it in all your volumes of NQF-
18 related material.

19 But the path I see us going down is
20 one, at maximum, there's low evidence or perhaps
21 insufficient evidence. We're going to be voting
22 on the sufficiency of that evidence first.

1 If it votes out as insufficient, then
2 we would be able to decide by the wisdom of this
3 group that there should be an exception that
4 despite having insufficient evidence, we think
5 this is important to measure. The evidence is a
6 must pass, and if it doesn't, then we stop our
7 discussion at that point.

8 I don't know if the NQF staff want to
9 add any additional comments or perspective.

10 DR. NISHIMI: I just want to clarify
11 that the questions you see on the evaluation
12 aren't the questions for voting. Those were to
13 guide your evaluation.

14 MEMBER MOYER: I guess I need some
15 clarity between what's low and what's
16 insufficient. It references U.S. Preventive
17 Services Task Force approach, and the Task Force
18 does not distinguish between low and
19 insufficient. Low is insufficient.

20 DR. NISHIMI: Low and insufficient
21 derive from the algorithm, so if you follow the
22 algorithm, you can conclude that sufficient

1 empirical evidence was provided and it will send
2 you right to moderate or low or you can conclude
3 that it was insufficient, and then the voting
4 would be, you know, is it insufficient but an
5 exception can be made because -- agree that it is
6 okay to hold providers accountable in the absence
7 of evidence because of the benefit to the
8 patient, so it becomes a risk benefit that you
9 weigh, or if you just don't feel that it is of
10 sufficient benefit, then you vote insufficient
11 with no exception.

12 CO-CHAIR SUSMAN: So, the question is,
13 what is the level of evidence? I think, from the
14 discussion, we're probably debating whether
15 there's low or insufficient evidence in this, and
16 then we'll consider --- if it's insufficient --
17 whether there's an exception or not.

18 Is that clear? Do people have --

19 MEMBER MOYER: I'm still unclear what
20 the difference between low evidence and
21 insufficient evidence. There's almost never a
22 question for which there's no evidence. There's

1 something out there.

2 CO-CHAIR SUSMAN: Yes. So, let me
3 read the boxes, and, hopefully, that will clarify
4 a little bit. It is a bit confusing. If you go
5 down the path here, is empirical evidence, or is
6 evidence submitted without systematic review and
7 grading?

8 And, you know, there really wasn't --
9 there isn't much evidence to systematically grade
10 or review here as I understand the presentation.
11 And, if that's no, it would take you to the next
12 page here, which takes you onto a path of
13 insufficiency.

14 On the other hand, if there is
15 empirical evidence submitted without systematic
16 review and grading, yes, that goes down to, does
17 the empirical evidence that is summarized include
18 all studies in the body of evidence? If the
19 answer is yes, does the agreement that the
20 submitted evidence indicates high certainty
21 benefits clearly outweigh undesirable effects or
22 risks?

1 And, then you get a distinction
2 between moderate, which I don't believe --
3 personally at least -- that we have here, or low,
4 or if there's little or no empirical evidence and
5 there's no real systematic evaluation of that.
6 That would take us to the orange boxes, and
7 you'll see here, or are there, or could there be,
8 performance measures of a related health outcome,
9 or evidence-based intermediate clinical outcome
10 or process?

11 Is there evidence of a systematic
12 assessment of expert opinion? And, I think, at
13 least in this case, one could argue that there
14 has been here.

15 And, does the Steering Committee --
16 all of us -- believe that it's okay beneficial to
17 hold providers accountable in the absence of
18 empirical evidence? If we don't believe that in
19 our second round of voting, if we come to a
20 conclusion it's insufficient, then you'd vote
21 against it and say, "No, you know, not only do I
22 believe there's insufficient evidence, I don't

1 think it is appropriate to hold people
2 accountable for this."

3 So, are there questions about the
4 algorithm?

5 CO-CHAIR BROOKEY: So, I think, the
6 question is a good one because you're asking
7 whether or not you're just going to go to one
8 pathway or the other. If you say it's low, it
9 stops, right? If you say it's insufficient, then
10 there's an opportunity to go ahead and let it
11 pass.

12 So, that's a very good distinction,
13 and I think we have to be clear about the
14 difference between low and insufficient. But I
15 think that left-hand bottom box is the key box to
16 look at, and we'll have to make a decision
17 whether we want it to move onto the second page.

18 Do you want to comment any more about
19 the distinction?

20 DR. NISHIMI: It's really the judgment
21 of the Committee as to whether the evidence
22 provided was systematically reviewed, which -- or

1 it's not a systematic review, and so if it's not
2 systematically reviewed, we know there's no
3 grading, but then that will send you down to the
4 no into the insufficient area.

5 But if you feel that, you know, the --
6 there was, you know, a lot of evidence that was
7 there, and it was reviewed, and it just happens
8 to be low, that sends you to the right. So, in
9 my mind, it's what's in your mind what
10 constitutes that without systematic review and
11 grading.

12 CO-CHAIR SUSMAN: David.

13 MEMBER KELLER: Yes, I'm sorry; I
14 thought I understood it, and then I was listening
15 to John, and now I don't.

16 (Laughter.)

17 CO-CHAIR SUSMAN: Good work, John.

18 MEMBER KELLER: So, I just want to be,
19 be clear. So, in order to pass this first
20 hurdle, you need to have either moderate or high
21 evidence?

22 DR. NISHIMI: No, you need to have --

1 the choices that will come up are high, moderate,
2 low, insufficient.

3 MEMBER KELLER: Okay. And, so,
4 insufficient doesn't move you -- so -- so --

5 DR. NISHIMI: And, then --

6 MEMBER KELLER: So, to Ginny's point,
7 any of those three high, low -- moderate, low,
8 move us to the next phase.

9 DR. NISHIMI: No. I'm confused about
10 what you're asking.

11 CO-CHAIR SUSMAN: So, if it's a rating
12 of low evidence, that does not move it. Is that
13 correct?

14 DR. NISHIMI: Correct.

15 MEMBER KELLER: That's what I wanted
16 -- okay.

17 CO-CHAIR SUSMAN: So -- so if you rate
18 it low --

19 MEMBER KELLER: Moderate or high does
20 move it.

21 CO-CHAIR SUSMAN: Moderate or high
22 would move it.

1 MEMBER KELLER: Okay.

2 CO-CHAIR SUSMAN: If it gets
3 insufficient, it doesn't automatically move
4 unless we vote for an exception.

5 DR. NISHIMI: Right.

6 CO-CHAIR SUSMAN: Is that --

7 DR. NISHIMI: So, if you can vote --
8 if you vote insufficient, then you can then
9 choose to vote insufficient with exception or
10 insufficient with no exception.

11 MEMBER MOYER: So, if there's a
12 systematic review that uncovers very little in
13 the way of evidence, but there is a systematic
14 review that's low, and we can't vote an exception
15 in that case.

16 DR. NISHIMI: Correct.

17 CO-CHAIR SUSMAN: That is correct.

18 MEMBER MOYER: So, the choosing
19 between low and insufficient is really more a
20 matter of deciding what we want to do next than
21 it is assessing the evidence.

22 CO-CHAIR SUSMAN: Could be.

1 DR. NISHIMI: You can decide it was
2 not sufficiently systematic. You know, to your
3 mind, not everything was presented, ergo it's
4 low. I mean, there are -- there are different
5 ways to get to low versus insufficient.

6 CO-CHAIR SUSMAN: I know this is a
7 somewhat confusing decision point, but just to
8 recap: if you vote low -- and the majority of us
9 go there -- we'll get to no further
10 consideration. If you vote insufficient, it will
11 either die or we will decide that there should be
12 an exception.

13 And, it should be rated on the level
14 of evidence as presented today and in the
15 materials provided, including the provision of
16 systematic review of clear evidence or not. And
17 --

18 MEMBER MOYER: Because the concern
19 that I'm continuing to have is that this means
20 that we're not -- we need to assess the evidence
21 and its -- the totality of the evidence, the body
22 of the evidence, independent of where that's

1 going to take us. First, we assess the body of
2 the evidence.

3 So, we shouldn't be deciding between
4 low and insufficient based on what we would like
5 to be able to do. We should be deciding between
6 low and insufficient based on whether it is low
7 or insufficient.

8 CO-CHAIR SUSMAN: I think -- I think,
9 you're right spot on. The algorithm is built in
10 a way that it separates out those decisions, so I
11 think we need to try to -- as much as possible --
12 adhere to the criteria and the processes
13 outlined.

14 DR. NISHIMI: But some will consider
15 the review that was provided to be -- some will
16 consider the answer to box seven no, and that
17 will send them down to insufficient. Some of you
18 will consider it to be yes, and that will send it
19 to the right.

20 That's a decision each of you make.
21 It's not something that you all have to
22 collectively -- it's a judgment call at that

1 point, so that's why I'm not being specific on
2 which direction it takes you. That's a decision
3 for you to make.

4 CO-CHAIR SUSMAN: So, are there any
5 other questions about this, or let's then learn
6 how to use our clickers. This is the first day
7 of medical school. We welcome you all here, or
8 PA school, or wherever you happen to be.

9 DR. NISHIMI: Severa.

10 CO-CHAIR SUSMAN: Professor Severa.

11 MS. CHAVEZ: Thank you. Okay. So, to
12 vote, please point your clicker at my laptop
13 here. And you can only vote once during voting
14 per PowerPoint, but you can change your vote at
15 any time during the ten seconds that we get to
16 vote by pressing on the number that correlates
17 with the answer that's shown on the PowerPoint.

18 Any questions?

19 MEMBER MILLER: Yes. This is Marlene.
20 Can you, you know, can you tell me the choices
21 that it's for?

22 MS. CHAVEZ: Marlene, I will read the

1 options since we're actually ready to vote.

2 MEMBER MILLER: Okay.

3 CO-CHAIR SUSMAN: Does anybody have
4 any questions about the use of the clicker?

5 (No audible response.)

6 CO-CHAIR SUSMAN: Are we going through
7 a practice clicker or --

8 DR. NISHIMI: We're going to see if we
9 can do it on the first try.

10 CO-CHAIR SUSMAN: All right. Okay,
11 this is high stakes. Okay. So, the choices --
12 Marlene and others on the phone -- one is high,
13 only eligible if the QQC, which is what?

14 DR. NISHIMI: Quality, consistency and
15 quantity of evidence.

16 CO-CHAIR SUSMAN: Okay. If it was
17 submitted, which we do not have, I think it's
18 safe to say.

19 Two is moderate, three is low, and
20 four is insufficient. So, let's go ahead and see
21 if we can vote.

22 MS. CHAVEZ: So, we're now voting for

1 Measure 2805, Pediatric Psychosis: Timely
2 Inpatient Psychiatric Consultation. Okay.
3 Ready.

4 CO-CHAIR SUSMAN: Okay.

5 MS. CHAVEZ: Go. I'm sorry.

6 (Pause.)

7 CO-CHAIR SUSMAN: I'm sorry, what did
8 you say?

9 MEMBER MILLER: I was just telling
10 Severa I sent in mine by the chat on the web
11 link.

12 CO-CHAIR SUSMAN: Got it.

13 DR. NISHIMI: We have it.

14 CO-CHAIR SUSMAN: And, there was one
15 recusal, that's correct. And, Jeff -- thank you,
16 Jeff.

17 Vote early; vote often.

18 DR. NISHIMI: So -- so the results for
19 evidence, 4 people voted for low and 11 for
20 insufficient.

21 CO-CHAIR SUSMAN: So --

22 DR. NISHIMI: Yes, we were expecting

1 24 votes.

2 CO-CHAIR SUSMAN: Okay. We're going
3 to redo this. Evidently, there was a
4 malfunction. We only had 15 or so votes there, I
5 think, and we have 24 expected. So, give us the
6 word and we'll try again.

7 MS. CHAVEZ: Okay. So, we're re-
8 voting. We're expecting 24 votes, 2 via -- via
9 chat. Okay. Ready. Go.

10 DR. NISHIMI: And, please point your
11 clicker directly to Severa.

12 CO-CHAIR SUSMAN: Okay. And, for
13 those on the phone, please vote now through your
14 chat function.

15 (Pause.)

16 MS. CHAVEZ: One more. Good. We got
17 it.

18 CO-CHAIR SUSMAN: All right. What?
19 Well, that resolve -- for those of you on the
20 phone -- has one person under moderate. We've
21 met the enemy, and it's IT.

22 (Laughter.)

1 CO-CHAIR SUSMAN: Would it be
2 acceptable to do a hand vote for this and --

3 MS. MUNTHALI: Yes.

4 CO-CHAIR SUSMAN: Okay.

5 DR. NISHIMI: We'll try it one more
6 time. We're going to do it one more time, and
7 then --

8 CO-CHAIR SUSMAN: Okay. We're going
9 to try the electronic version again. Again, for
10 those of you over the phone, please register your
11 votes via chat function. Let's wait just a
12 second until our technical wizards are ready.

13 MS. CHAVEZ: Okay. Ready.

14 CO-CHAIR SUSMAN: Okay. Let's vote.

15 (Pause.)

16 DR. NISHIMI: I see 25 responses. Why
17 does it say 29?

18 CO-CHAIR SUSMAN: Remember, we have
19 two on the phone.

20 MS. ALLEN: Okay. We need to --

21 DR. NISHIMI: Until we get this sorted
22 out, we're going to just go ahead with a hand

1 vote.

2 Lauren and Marlene, if you could say
3 your vote over the phones? State your name first
4 and then your vote. We'll start out with Marlene
5 and Lauren.

6 MEMBER MILLER: This is Marlene; I
7 vote low.

8 MEMBER AGORATUS: This is Lauren; I
9 vote moderate, but I always vote high, so --

10 CO-CHAIR SUSMAN: There are always
11 one, yes. Thank you.

12 DR. NISHIMI: Okay. Anyone in favor
13 of high?

14 (Show of hands.)

15 DR. NISHIMI: Moderate?

16 (Show of hands.)

17 DR. NISHIMI: Low?

18 (Show of hands.)

19 CO-CHAIR SUSMAN: Keep your hands
20 raised until they've got them all. It's a very
21 technical process; it involves high-speed
22 computing.

1 And, finally, insufficient. And,
2 remember, we have one recusal.

3 (Show of hands.)

4 CO-CHAIR SUSMAN: You can't see --

5 MS. ALLEN: For the record, --

6 CO-CHAIR SUSMAN: Yes, please.

7 MS. ALLEN: For the record, we have 0
8 high, 1 moderate, 6 low, and 16 insufficient.

9 CO-CHAIR SUSMAN: So, the
10 insufficients have it.

11 And, now we would consider a motion to
12 consider an exception if that is the will of the
13 group or not.

14 (Show of hands.)

15 CO-CHAIR SUSMAN: So, there is a
16 motion on the table. A second?

17 (Show of hands.)

18 CO-CHAIR SUSMAN: Okay. To consider
19 an exception, and remember that the exception
20 here is: does the Steering Committee agree that
21 it's okay or beneficial to hold providers
22 accountable for performance in the absence of

1 empirical evidence of benefits to patients?
2 Consider potential detriments to endorsing the
3 measure -- for example, focus attention away for
4 more impactful practices -- more cost without
5 certainty of benefit, divert resources from
6 developing more impactful measures.

7 So, we have a vote of either an
8 exception, which will be our first or second no
9 exception. And, we'll be taking the vote on the
10 phone first, and then we'll take the vote of the
11 group here present.

12 DR. NISHIMI: Okay. Severa.

13 MS. CHAVEZ: Okay. So, for the
14 benefits of the ones on the phone, one is
15 insufficient evidence with exception, and two is
16 no exception. So, we'll try voting again using
17 our clickers. Hold on. All right.

18 CO-CHAIR SUSMAN: And, for those of
19 you on the phone, try to use the chat function.

20 MS. CHAVEZ: Okay. Go.

21 (Pause.)

22 MS. CHAVEZ: Twenty-two. Twenty-four,

1 okay. So, 11 voted insufficient evidence with
2 exception; 13 voted no exception.

3 (Off microphone comment.)

4 MS. CHAVEZ: Yes. And, we have -- we
5 have 25 Committee members right now voting with
6 one recusal, so 24 votes.

7 (Off microphone comment.)

8 MS. CHAVEZ: Yes. Yes. Somebody --

9 CO-CHAIR SUSMAN: Yes. So, just to
10 clarify. There was one recusal -- two on the
11 phone that our staff assured were in the count --
12 and it's 11 voted for an exception, while 13
13 voted against; therefore, there's no exception.
14 Therefore, the consideration of this measure now
15 stops.

16 I will take a moment of privilege to
17 ask if there's any further feedback to the
18 developers. They've obviously spent a lot of
19 hard work doing this, and clearly, this was a
20 very divided group of folks. I think, we all had
21 a sense that this is an important issue, and yet
22 the body of evidence is not as well-developed

1 perhaps as it should be.

2 Any other feedback or suggestions?

3 Yes, please.

4 MEMBER MORROW-GORTON: I would just
5 suggest that you consider going back and looking
6 at the whole population of children who presented
7 with psychotic symptoms, to sort of divvy out who
8 those kids where that didn't have a psychotic
9 diagnosis at the end, and that you look at the
10 age groups.

11 CO-CHAIR SUSMAN: So, there's been
12 some feedback about the age group, looking at
13 presenting population of those with psychotic
14 symptoms.

15 Any other feedback?

16 (No audible response.)

17 CO-CHAIR SUSMAN: Again, I want to
18 thank you very much for your clear, concise
19 answers. I know it's a lot of hard work, and I
20 recognize you're probably disappointed, but thank
21 you very much.

22 We were supposed to be taking a break

1 at 10:30, so we have a decision point of whether
2 to go on and do our next -- we're about a half
3 hour ahead -- or whether to take a break now,
4 instead. So, without using the clickers, how
5 many would you like to take a break now? Raise
6 your hands.

7 (Show of hands.)

8 CO-CHAIR SUSMAN: And how many would
9 like to press on?

10 (Show of hands.)

11 CO-CHAIR SUSMAN: Only a few, so we're
12 going to take a 15-minute break; that should get
13 us back here at 10:15. Thank you very much.

14 (Whereupon, the above-entitled matter
15 went off the record at 10:00 a.m. and resumed at
16 10:17 a.m.)

17 CO-CHAIR SUSMAN: Okay, you don't get
18 to vote if you aren't at the table. So, I know
19 that is an incentive.

20 Okay, so our esteemed colleagues from
21 the Seattle Children's Research Institute and
22 UCSF will come back for a second round here. I

1 think, what, a three-round -- three rounds, okay.

2 This is consideration of Pediatric
3 Psychosis: Screening for Drugs of Abuse in the
4 Emergency Room. It is Measure 2806.

5 First of all, let me ask if there are
6 any recusals for this one. Jeff or others?

7 Any further recusals, on the phone?
8 Okay, so let's turn to our developers for a brief
9 description and context. Thank you.

10 DR. BARDACH: Thank you. As I
11 mentioned before, we used the same process to
12 develop this measure as we used for 2805. So,
13 there is a lit review, a multi-stakeholder Delphi
14 panel, and then field testing.

15 This measure focuses on the pediatric
16 patient scene in the emergency department. It is
17 a medical records-based measure of the percent of
18 children and adolescents age 5 to 19 years old
19 with a discharge diagnosis from the ED of
20 psychosis who are screened for alcohol or drugs
21 of abuse while in the ED. The intended level of
22 measurement is at the hospital level, which are

1 the results that we present.

2 We would like to just briefly address
3 the most major concern brought up in the working
4 group call regarding the appropriateness of this
5 measure for the younger age group. In order to
6 do this, we looked at our data by age groups.
7 For this measure, 26 of the eligible patients or
8 10 percent of them were in the younger age group
9 between 5 and 10 years old. And performance
10 differed in a statistically significant way
11 between the two groups with a mean score of 6 for
12 the younger kids and a mean score of 31 for the
13 older kids. This supports the committee members'
14 concern that younger patients might be treated
15 differently. And so we're amenable to responding
16 to the concern by narrowing the age range for the
17 measure to only include patients 12 years or
18 older.

19 That's all we have to say.

20 CO-CHAIR SUSMAN: Okay, thank you.

21 Short and sweet. So, we have Kevin, Karen,
22 Martha. Kevin, you are first listed. And if you

1 would please just give us a quick overview and
2 focusing on the conceptualization of the measure
3 and the evidence.

4 MEMBER SLAVIN: So, as mentioned, this
5 is a measure regarding screenings for drug of
6 abuse for children who present to the ED with
7 psychosis. And sort of looking through the
8 actual measurement, it seems fairly
9 straightforward. The evidence I think we are
10 going to find in discussion is going to be
11 similar to the last measure in that there really
12 isn't a lot of empiric evidence one way or the
13 other. However, if you look sort of beneath the
14 surface, if this is a measure designed to
15 identify children or youth with psychosis who
16 have substance abuse, there certainly is a lot of
17 information about the rates of substance abuse in
18 youth with psychosis.

19 Most of the measure's recommendations
20 come from the AACAP Guidelines but it is
21 important to note that within the guideline for
22 the recommendation for screening for drug abuse

1 or drugs that can be abused and alcohol, they do
2 have an out which says exposure to drugs or
3 alcohol cannot otherwise be ruled out. And that
4 actually raises, in my mind, some questions about
5 the actual practicality of this measure.

6 From a reliability perspective and
7 validity, we will talk a lot more about that, as
8 we sort of go on.

9 Actually, just getting to the gap,
10 because I guess that is the second item on there,
11 if you look at the measure as they tested it,
12 there was actually -- seemed to be a decent
13 spread of gap in the performance that was not
14 just specifically based on the age ranges with,
15 interestingly, some of the smaller hospitals
16 performing better than some of the larger
17 hospitals.

18 When looking at reliability, there may
19 be some questions that come up about sort of the
20 ranking of where psychosis appears in the list of
21 diagnoses that somebody may present with because
22 it does sort of focus on the first and second

1 diagnoses for the measure at the discharge
2 diagnosis. And it is possible, I don't want to
3 say likely, but it is possible or perhaps even
4 probable that psychosis may not be one of the top
5 two diagnoses for that particular ED visit but
6 that doesn't mean that the screening shouldn't
7 necessarily be done.

8 Validity, we will talk more about that
9 process, I'm presuming, if we get past the
10 evidence part.

11 So, I don't know if there is any other
12 things people wanted to bring forward or discuss.

13 CO-CHAIR SUSMAN: Well, why don't we
14 work with that and then as we proceed, we can get
15 in further depth?

16 Other comments from the primary
17 reviewers? Yes.

18 MEMBER BERGREN: Well, I had actually
19 interpreted it differently as I thought it was to
20 be looking at children who presented with
21 psychotic symptoms -- symptoms of psychosis but
22 not diagnosed psychosis and then ruling out drugs

1 or alcohol as a cause of those symptoms.

2 DR. MANGIONE-SMITH: So, actually, it,
3 again, is looking at children who were in the ED
4 and diagnosed with psychosis. So, again, the
5 eligible population is identified using
6 administrative claims data and the diagnosis of
7 psychosis by ICD-9 codes. And what we are
8 looking for here is comorbid substance use, which
9 is very known to be a common phenomenon in
10 children with psychotic disorders and is commonly
11 missed. And if it is missed and untreated,
12 obviously, has bad consequences.

13 MEMBER BERGREN: Okay.

14 CO-CHAIR SUSMAN: Thank you.

15 MEMBER SLAVIN: And actually if I --
16 I'm sorry.

17 CO-CHAIR SUSMAN: Go ahead, please.

18 MEMBER SLAVIN: No, that was one of
19 the concerns I had but if you read the measure in
20 the way it is described, it talks a lot more
21 about the comorbidities but one of the concerns
22 is that the measure actually measures two

1 different things because it does, since it is
2 based on the ED assessment, it does also seem to
3 be looking at potential acute triggers for
4 psychosis, in terms of like the reliability and
5 validity of the measure raises some concerns in
6 my mind about how it is actually applied, rather
7 than so much what the intent of the measure is.

8 CO-CHAIR SUSMAN: Okay, I see some
9 hands up, so to speak. Maureen.

10 MEMBER EDIGER: Mine is just a
11 procedural question. Is it an option for us to
12 consider it as amended on the different age
13 group?

14 CO-CHAIR SUSMAN: No. As I understand
15 it, NQF staff, please correct me if I am wrong,
16 we need to look at it as specified currently. If
17 through our process this is sent back, they could
18 make that change and then, through relatively
19 rapid turnaround, get it back if they wanted to
20 change the age specification.

21 But what we need to do is look at it
22 as specified and with the same age. Correct?

1 I'm seeing a lot of nodding heads.

2 DR. NISHIMI: If they have the data on
3 testing and can bring it back in a fast
4 turnaround, then the committee can reconsider it
5 at the post-comment phase. But today, you vote
6 on it as you see it.

7 CO-CHAIR BROOKEY: Just to clarify,
8 Robyn, if a member would like for it to come back
9 as amended, should they just provide their input
10 today?

11 DR. NISHIMI: Yes, the feedback that
12 you give the developer will help inform their
13 decision-making, obviously.

14 CO-CHAIR SUSMAN: So, as I did with
15 our first measure, depending on our outcome, I
16 will ask for feedback to each of the developers
17 so that we can give them some benefit of your
18 expert guidance.

19 Okay, Amy, thank you. I have got a
20 spotter here now.

21 MEMBER HOUTROW: I just wanted to make
22 sure I understood this correctly. So, if someone

1 presents with psychotic features in the ED and is
2 discharged from the hospital with psychosis as
3 their diagnosis, then we are looking for the
4 comorbid percentage of children who have drug or
5 alcohol abuse. But what about the children who
6 presented to the ED who then were diagnosed with
7 acute drug overdose and then, therefore, weren't
8 discharged with a diagnosis of psychosis? Those
9 children are no longer in the denominator. Is
10 that right?

11 CO-CHAIR SUSMAN: What's the response?

12 DR. NISHIMI: That's correct.

13 CO-CHAIR SUSMAN: Okay, was there
14 another comment?

15 MEMBER FINKELSTEIN: So, it is kind of
16 back to the process thing and I don't want to be
17 too obsessive about this but if that were the
18 case, if we thought that the age range really
19 mattered and that that was the reason to vote no
20 on what the specified measure is we are looking
21 at today, would that be at the phase we were at
22 before in the evidence phase or would that be at

1 the validity phase, where we didn't move it
2 forward?

3 DR. NISHIMI: Could be at either.

4 CO-CHAIR SUSMAN: Does that help?

5 MEMBER FINKELSTEIN: Yes. It is that
6 the box about the exception or not that is
7 unclear to me whether we have to be strictly
8 about as it is written or whether, with a change,
9 it could have an exception and it is a tweak that
10 it needs.

11 CO-CHAIR SUSMAN: Well, I think you
12 know we have to stick to what was submitted, as
13 submitted. And anything that we would think of
14 as tweaks, we can provide as feedback. But what
15 we are voting on today is the documentation,
16 materials, and the clarification provided by the
17 developers.

18 Kevin.

19 MEMBER SLAVIN: If it helps in the
20 AACAP Guideline that is quoted, it says
21 specifically youth. It does not say children and
22 youth, as the citing for the recommendation for

1 testing. So, that was one of the questions that
2 I had was what prompted the age range to be
3 extended down from youth to five years of age.

4 And the second thing is I think the
5 measure, as it is reported, the diagnosis of
6 psychosis is based on the ED diagnosis, not the
7 inpatient diagnosis. And you can correct me if I
8 am wrong but that is the way that I read the
9 denominator statement.

10 DR. NISHIMI: That's true. It is only
11 ED patients. So, it is patients discharged from
12 the ED with a discharge diagnosis from the ED of
13 psychosis. Thanks for asking for clarification.

14 MEMBER MOYER: If they are discharged
15 to inpatient care, is that still a discharge or
16 do you mean discharged to home?

17 DR. NISHIMI: Discharged to home.

18 MEMBER MOYER: So, a kid who comes
19 into the ER psychotic and so forth and gets
20 admitted would not fall into this group.

21 DR. NISHIMI: That's right. Sorry,
22 let me just double check one second. I'm almost

1 sure that is right.

2 MEMBER MOYER: Yes, if they either got
3 admitted or they got transferred to a psychiatric
4 facility, one would assume they still needed to
5 be evaluated.

6 CO-CHAIR SUSMAN: Okay, we will get an
7 answer on that. I will go to Debbie in the
8 meantime.

9 MEMBER FATTORI: Can the developers
10 explain the rationale for choosing the age range
11 that you decided on?

12 DR. MANGIONE-SMITH: Yes, actually we
13 can.

14 MEMBER FATTORI: Thanks.

15 DR. MANGIONE-SMITH: This is,
16 unfortunately, gets back again to the Delphi
17 panel having very clear opinions about age ranges
18 for the different sets of measures we have
19 presented to them. We presented to them measures
20 on psychosis, measures on danger to self and
21 suicidality and measures on substance abuse.

22 The substance abuse measures, which

1 you are not seeing any of today, were 12 to 19
2 years old. This one was a psychosis measure and
3 they said oh, the psychosis measure should be 5
4 to 19. And this, unfortunately, slipped under
5 the radar of this is actually about substance
6 abuse and should have been 12 to 19. So, it was
7 unfortunate that that is what happened.

8 CO-CHAIR SUSMAN: Okay, such things
9 happen. I wonder if the folks who reviewed this
10 more closely could speak again to the evidence.
11 Was there a real systematic review? How was that
12 conducted? I understand there was a Delphi
13 process but one of the key judgments we have to
14 make upfront here is about the quality of
15 evidence. And so far, I am getting a sense that
16 we are back to this issue of low or insufficient
17 evidence. So, Kevin, I don't know if you want to
18 address it or one of the other.

19 DR. NISHIMI: Can I address the prior
20 question?

21 CO-CHAIR SUSMAN: Okay, yes, address
22 the prior question before we go on to something

1 else.

2 DR. NISHIMI: Sorry. There was just
3 one outstanding question. So, patients who are
4 seen in the ED, they needed to get the drug or
5 urine or drug or alcohol testing done in the ED
6 before getting either discharged or admitted to
7 hospitals. So, it did include inpatients as
8 well. Yes, they had a discharge diagnosis. The
9 diagnosis was made in the ED before they went up.

10 CO-CHAIR SUSMAN: So does that mean,
11 just for clarification, if someone was admitted
12 and then it was on their admission orders that
13 didn't count if it was done by say general
14 medicine or general psychiatry?

15 DR. MANGIONE-SMITH: That's exactly
16 right. So, the ED would be held accountable for
17 having done that testing.

18 CO-CHAIR SUSMAN: So, you are really
19 looking at accountability at the ED level, as
20 opposed to a more systems-level.

21 DR. MANGIONE-SMITH: Simply because we
22 thought there would be a fair number of children

1 seen in an outside ED and sent somewhere else.

2 And we wanted to make sure that the index ED was
3 being accountable for the testing.

4 CO-CHAIR SUSMAN: Okay. I'm sorry for
5 that interruption but you are waiting with bated
6 breath.

7 MEMBER SLAVIN: No, I'm just waiting.

8 (Laughter.)

9 MEMBER SLAVIN: So, this gets into the
10 discussion similar to the evidence discussion
11 from the previous measure. I can't tell you for
12 sure that it is the same AACAP Guideline or
13 practice recommendation that this comes from but
14 it is part of that same process, where there is
15 not a lot of empiric evidence stating that this
16 screening has an impact on outcomes. There is,
17 certainly, a lot of data suggesting that there is
18 a higher rate of substance abuse in this
19 population. If you look at the adult literature,
20 most of that is tobacco use, which is not
21 screened for in the panels that are suggested.
22 On the other hand, that is, I think, not what

1 this measure is really designed to focus on.

2 This particular recommendation for
3 this measure comes from the consensus panel that
4 reviewed the literature. So, it seemed like it
5 was an overwhelming consensus but it was not
6 based on empiric evidence that stated that it
7 improved short-term or long-term outcomes.

8 CO-CHAIR SUSMAN: Okay, thank you.
9 Other questions? Yes, please, David.

10 MEMBER EINZIG: And I'm not sure if
11 this is illustrated in the proposal here but just
12 playing the common sense card, it does make
13 absolute clinical sense, and again, have a direct
14 correlation with outcome if they are chronic
15 alcohol abusers or benzodiazepine users and that
16 is not picked up, they get admitted to the floor
17 in the psychiatric hospital and they get
18 withdrawal seizures, DTs. I don't think that is
19 illustrated in here but there is evidence it
20 should be quality of care.

21 CO-CHAIR SUSMAN: Okay. Other
22 comments or questions? Yes, Ricardo.

1 MEMBER QUINONEZ: I just have a quick
2 question. When we are talking about -- and I did
3 read the measure but I don't remember these
4 specifics. When we are talking about drug
5 testing, are we talking about a UDS or are we
6 talking about a comprehensive drug testing or
7 what are we?

8 DR. NISHIMI: I can read you
9 specifically what the instructions to the
10 abstractors was. Indicate if the patient had a
11 urine drug screen or serum alcohol screen while
12 in the ED. The alcohol test will be a separate
13 test from the drug test. The drug test must be
14 comprehensive in that it tests for multiple types
15 of illicit drugs. Do not give credit for tests
16 that include results of just a single drug. And
17 then it helps the abstractor. Drug screens
18 commonly include tests for benzodiazepines,
19 barbiturates, methamphetamine, cocaine,
20 methadone, opiates, tetrahydrocannabinol, et
21 cetera.

22 MEMBER QUINONEZ: Okay. Well, was

1 there any discussion during your Delphi panel
2 whether there was concern about how reliable
3 urine drug screen tests are? I always remember
4 toxicologists saying you know a urine drug test
5 was never really developed for what it is used
6 today and it misses a lot of things and it cross-
7 reacts with a lot of things.

8 DR. MANGIONE-SMITH: It wasn't
9 discussed.

10 MEMBER QUINONEZ: Okay.

11 CO-CHAIR SUSMAN: David Keller.

12 MEMBER KELLER: The other David down
13 here. So, this kind of builds off of those last
14 two questions and I am wondering if the measure
15 developers gave any consideration to using non-
16 laboratory screening for substance abuse, as
17 opposed to using a drug test, particularly around
18 the issue of alcohol, which is the most prevalent
19 drug used in adolescents in general and I
20 suspect, also, in adolescents who present with
21 psychosis.

22 DR. MANGIONE-SMITH: So we actually

1 did have a measure that looked at alcohol
2 screening, using a validated screener in the ED.
3 And performance was so low across all five
4 hospitals, that we felt that using validated
5 screeners cannot be used as a standard of care at
6 this point in time because adoption is so poor.
7 They all scored under ten percent on a zero to
8 hundred scale on that measure.

9 CO-CHAIR SUSMAN: And when you say so
10 low, it is their actual use, not their
11 performance?

12 DR. MANGIONE-SMITH: We couldn't find
13 any screens in the patients we thought they were
14 indicated for.

15 CO-CHAIR SUSMAN: Okay.

16 DR. NISHIMI: It's not that so few
17 patients screened positive. It is that so few
18 hospitals --

19 CO-CHAIR SUSMAN: Right. Or that the
20 reliability of screening in psychotic kids was
21 poor.

22 Okay, on the phone, are there any

1 comments?

2 MEMBER MILLER: No. This is Marlene.
3 I think I am still kind of stuck in the early
4 comments of where we are in terms of the first
5 measure, in terms of just the overall evidence
6 has been looking at guidelines and the
7 extrapolations from it from youth to all these
8 ages is relatively weak.

9 CO-CHAIR SUSMAN: So, there is still
10 some of I think the same evidence concerns.

11 Jon, do you have a comment or
12 question?

13 MEMBER FINKELSTEIN: My comment would
14 be for me it is even more clear that the evidence
15 is insufficient but, in my view, the credible
16 information we have about professional consensus
17 is stronger here. So, as I go through the orange
18 boxes on page two, deciding whether this should
19 be with exception or not, it seems to me both
20 clinical practice-based validity, the Delphi
21 process the developers went through and the
22 guideline of the profession are all right on

1 target that this should be done. I think we have
2 this issue of the age group. But absent that, I
3 think this is one that I would rate as
4 insufficient with exception.

5 CO-CHAIR SUSMAN: Okay, John.

6 CO-CHAIR BROOKEY: Just a quick
7 question about specs. I'm picky about the lab
8 results, whether they were ordered or whether
9 they resulted and whether there is evidence that
10 people acted on the result. Is that included in
11 the specs?

12 DR. NISHIMI: Yes, so great questions
13 and important in terms of operationalizing. It
14 is just the instructions to the abstractor is
15 just whether or not the patient had a drug screen
16 or serum alcohol screen while in the ED.

17 CO-CHAIR SUSMAN: Ordered while in the
18 ED or resulted while in the ED?

19 MEMBER SLAVIN: I believe it specifies
20 resulted because if you read the specs very
21 carefully, it talks about not likely to miss lab
22 results because of the chain of what happened.

1 So, it is based on whether or not it is resulted,
2 not based on whether or not it is ordered, which
3 was one of the questions that I had because many
4 of these patients, in terms of obtaining urine
5 for a drug screen are not necessarily going to be
6 as cooperative as we would hope. And so, and
7 there are issues with elopement and leaving AMA
8 before specimens are actually collected. So,
9 there may be an attempt to try to collect them
10 but not actually obtain the specimen for testing.

11 CO-CHAIR SUSMAN: And on the other
12 hand, I could imagine a very efficient system,
13 where the person is transferred to their ultimate
14 destination, whether on the floor and results are
15 gotten up there and where information is shared
16 in a good manner or not.

17 MEMBER SLAVIN: Are any of these
18 admissions ever efficient?

19 (Laughter.)

20 CO-CHAIR SUSMAN: Well, you know I am
21 sure there must be the perfect hospital
22 somewhere.

1 Okay, it looks like we are gaining
2 consensus about where we want to be here. So our
3 first question will be voting on the evidence.
4 And Kevin?

5 MEMBER SLAVIN: Actually, I just had
6 one more question. I'm not sure if it would fall
7 under here or not but it was the numerator, the
8 part about the numerator that allows for, for
9 want of a better word, partial credit for one or
10 the other, if that could be explained a little
11 bit why this isn't an all or none.

12 DR. MANGIONE-SMITH: So, the decision
13 among those of us who were operationalizing the
14 measure was that if you had done say a serum
15 alcohol test but you hadn't done the urine drug
16 screen, we wanted to give you credit for at least
17 doing part of the right thing. So, that was just
18 a decision of us as a development team that you
19 should get partial credit. You get 50 percent if
20 you did one and not the other.

21 CO-CHAIR SUSMAN: So, how would that
22 be reported on a system level? Was it a

1 facility-level process measure?

2 DR. MANGIONE-SMITH: So, it would roll
3 up for every eligible patient. So, you would
4 either have a zero --

5 CO-CHAIR SUSMAN: You have to have two
6 50 percents to equal one?

7 DR. MANGIONE-SMITH: So, you would
8 score either 0.5 or 1.0. And then you roll it up
9 among all eligible patients to get your overall
10 score, which was still terrible.

11 CO-CHAIR SUSMAN: Got it.

12 Okay, let's go ahead, then, and get up
13 our screen for important to measure the evidence.
14 Remember, for those on the phone, one is high,
15 two is moderate, three is low, and four is
16 insufficient. And are we in clickerville today?

17 MS. CHAVEZ: Yes. Thank you, Dr.
18 Susman, for doing that for Lauren and Marlene.

19 Okay, so we are now voting on evidence
20 for Measure 2806, Pediatric Psychosis: Screening
21 for Drugs of Abuse in the Emergency Department.

22 We have increased the time period to

1 15 seconds and we are, again, expecting 24 votes
2 because we do have one recusal.

3 CO-CHAIR SUSMAN: So, please point
4 your clickers. Click away. And we will get our
5 votes from our outside, in the electrons
6 panelists.

7 And it looks like --

8 MS. CHAVEZ: So, I see 23 responses.
9 We have to do it again.

10 CO-CHAIR SUSMAN: Okay, we will do it
11 again. We have one recusal and 24 otherwise. Is
12 that correct?

13 MS. CHAVEZ: Everyone in the room.
14 Yes, I don't see -- oh, we are not ready. Sorry.

15 CO-CHAIR SUSMAN: Hold on. And again,
16 for those of you on the phone, if you could let
17 it be known through the chat function, we are
18 still dealing with electronics here.

19 MS. CHAVEZ: Okay. All right, ready,
20 go.

21 CO-CHAIR SUSMAN: Okay.

22 MS. CHAVEZ: One more.

1 DR. NISHIMI: Does anyone have a
2 neighbor missing?

3 CO-CHAIR SUSMAN: Now, we have all
4 moderate. If we work hard, we will get all high.

5 (Laughter.)

6 CO-CHAIR SUSMAN: The developers will
7 rejoice.

8 DR. NISHIMI: Okay, we're just going
9 to have to do a hand vote. There is a problem
10 here.

11 CO-CHAIR SUSMAN: So, let's go ahead
12 and have our two respondents on the phone.

13 MS. ALLEN: So, Lauren and Marlene,
14 staff will be voting for you in the room. We
15 already have your votes via the chat. So you
16 don't have to announce your vote.

17 DR. NISHIMI: Okay. High?

18 Moderate?

19 Low?

20 Insufficient?

21 CO-CHAIR SUSMAN: Well, clearly, the
22 insufficients have it. The counts will be up in

1 just a moment.

2 DR. NISHIMI: Okay, we actually have
3 to have the numbers because we record the numbers
4 in the report.

5 So, insufficient?

6 CO-CHAIR SUSMAN: Again, hands high.
7 We have multiple counters now. If you want a
8 bribe for your vote, now would be the time.

9 DR. NISHIMI: There were 19
10 insufficient. How many lows? Severa, how many
11 lows?

12 MS. CHAVEZ: Two lows.

13 DR. NISHIMI: Three.

14 MS. CHAVEZ: So, 19 insufficients; 3
15 lows; and that would make it 2 moderates.

16 CO-CHAIR SUSMAN: All right, so,
17 insufficient.

18 We will now entertain whether there
19 should be an exception here. As we discussed
20 during the first measure, this is an issue of do
21 we think it is important, despite the evidence
22 that this be endorsed, potentially, for both

1 accountability and for improvement purposes.

2 So, are we trying the electronic
3 version again?

4 DR. NISHIMI: Yes, let's try.

5 CO-CHAIR SUSMAN: Okay, we are going
6 to try the electronic version. For those of you
7 on the phone, one is insufficient evidence with
8 exception. In other words, you're voting
9 exception and two is no exception.

10 Yes?

11 MEMBER MOYER: The question is about
12 the point in the discussion where we would bring
13 up the age range. Because at this point, in
14 terms of no exception or exception, the age range
15 is one of the most critical pieces of
16 information.

17 CO-CHAIR SUSMAN: Yes, so I think,
18 unfortunately, the age range is as currently
19 specified and we need to vote on whether, as
20 specified, it makes sense to have this with
21 exception if, for example, one believed that the
22 specification around the younger folks in this

1 cohort was inappropriate, then one would vote
2 their conscience about this.

3 We could, if we got to the point where
4 this wasn't voted with exception, provide
5 feedback to our measure developers who have
6 obviously already thought about this issue in the
7 deliberations.

8 Jon, please put on your mike.

9 MEMBER FINKELSTEIN: Just to say it.
10 So I know we are in a very structured process but
11 I am a little concerned about the process just in
12 this way. If that is the only thing for some of
13 us holding this back and we think there could be
14 a rapid cycle reconsideration on a call a few
15 weeks from now, not to have gotten to talk about
16 the validity, the reliability and the measure
17 testing, will really set us back. I don't know
18 how we will --

19 DR. NISHIMI: You would talk about it
20 on the call.

21 MEMBER FINKELSTEIN: So, will there
22 really be time for that? If that is the process,

1 I understand.

2 DR. NISHIMI: That is the process and
3 you would then proceed. If it then passed
4 forward, you would then proceed to discuss it.

5 CO-CHAIR SUSMAN: Okay, Kevin, did you
6 have a --

7 MEMBER SLAVIN: Well just in regards
8 to that question. One of the key factors for the
9 validity part of this is whether or not it is
10 related to a true quality outcome. And, in my
11 mind, the age issue falls under the validity
12 portion not under the evidence portion, although
13 the evidence was not cited with this age range in
14 mind. So, it could be looked at probably either
15 way.

16 CO-CHAIR SUSMAN: There is probably
17 overlap between the two in this regard.

18 DR. NISHIMI: That's why I answered
19 the original question it could be in.

20 CO-CHAIR SUSMAN: Okay, any other
21 questions or points prior to vote?

22 MEMBER HOUTROW: I have a concern.

1 CO-CHAIR SUSMAN: Oh, I'm sorry, I
2 can't see.

3 MEMBER HOUTROW: If we are going to
4 use the clickers but we are going to have no
5 verification that the clicking that we did is
6 accurate -- because if we are really making a
7 decision whether this goes to a next part of the
8 discussion, I think we need to do some sort of
9 check to make sure if we are using the clicker
10 that the clicker accurately represented what our
11 votes were.

12 DR. NISHIMI: The clicking, the
13 problem we are having is when we have to reset it
14 because we didn't have enough votes. So, I don't
15 have a concern de novo. Remember we only had,
16 whatever it was, 22 and we were supposed to have
17 24. So, then when we reset it, that is when the
18 problem came in and we are going to work on that
19 at lunch.

20 CO-CHAIR SUSMAN: So, I think we are
21 ready here. Again, for benefit of those on the
22 phone, one is insufficient evidence with

1 exception and two is no exception. Severa, are
2 we ready to vote?

3 MS. CHAVEZ: I think. Yes. Ready,
4 go.

5 DR. NISHIMI: Please remember to point
6 your click in Severa's direction.

7 CO-CHAIR SUSMAN: So, we have 22
8 there.

9 MS. CHAVEZ: The software collected 22
10 responses. Nadine and yes, Robyn.

11 CO-CHAIR SUSMAN: There should be 24.
12 So, I would suggest we do the hands again. I
13 think the point is well taken about making sure
14 that we get this right, since it is so close.

15 DR. NISHIMI: Yes, we have -- so
16 voting for one, insufficient with exception.

17 CO-CHAIR SUSMAN: Voting for one,
18 insufficient evidence with exception.

19 DR. NISHIMI: So, 16.

20 CO-CHAIR SUSMAN: And I guess just as
21 a check --

22 DR. NISHIMI: No exception.

1 CO-CHAIR SUSMAN: Okay, 16 plus 8
2 equals 24. All right, good work.

3 So, this is actually recommended to go
4 forward with exception. And now we will go on to
5 the gap or opportunity for improvement. Is that
6 correct?

7 DR. NISHIMI: That is correct.

8 CO-CHAIR SUSMAN: And so the group who
9 reviewed this closely, is there good evidence for
10 a gap or opportunity for improvement?

11 MEMBER SLAVIN: I don't want to be the
12 only one who speaks.

13 CO-CHAIR SUSMAN: Yes, your teammates
14 are letting you down there.

15 MEMBER SLAVIN: You know in their
16 testing, this was tested at three children's
17 hospitals and two community hospitals. The
18 volumes in a couple of the hospitals were fairly
19 low. One had only 15 patients over the two-year
20 period; one had only 18 patients over the two-
21 year period. The range that they identified for
22 performance was basically 18 percent to 83

1 percent. Interestingly, the hospital with the
2 second smallest eligible patients, they had one
3 of the best performances. So, in looking at
4 this, it seems like there seems to be consensus
5 that this should be done. And so there is a
6 performance gap in terms of its not being
7 implemented across the board and there is also a
8 wide performance gap in the different hospitals
9 in their emergency departments.

10 CO-CHAIR SUSMAN: Thank you. Any
11 additional comments from our panelists?
12 Questions?

13 If not -- oh, yes, please.

14 MEMBER MOYER: Very briefly, from the
15 developers, the data on the younger kids in terms
16 of a gap.

17 DR. BARDACH: Sorry. You want us to
18 just give you the data on the younger kids again,
19 on performance?

20 MEMBER MOYER: Yes, are there data in
21 terms of the gap on the younger kids, the under
22 12s?

1 DR. BARDACH: Oh, where we just looked
2 at the under 12 and seeing the range.

3 CO-CHAIR SUSMAN: Did you stratify by
4 age?

5 DR. BARDACH: I don't think we looked
6 at the performance range.

7 CO-CHAIR SUSMAN: They are arguing.
8 Hold on.

9 DR. BARDACH: Hold on one second. Let
10 me just look it up. We may or may not actually
11 have it. We have it actually for the older age
12 group but not for the younger age group, the
13 range in performance variation, if that makes
14 sense.

15 But you are specifically interested in
16 the range of performance variation in younger
17 children rather than older children. It was only
18 five percent of our sample. So, I anticipate
19 that it is going to be very difficult to say
20 anything without just looking at noise.

21 MEMBER MOYER: That may be enough
22 information, just to know that we actually don't

1 have a clue in that age range.

2 DR. BARDACH: Yes, I think that is a
3 fine conclusion.

4 CO-CHAIR SUSMAN: Anything else you
5 want to say, Kevin, on this?

6 MEMBER SLAVIN: I think the numbers
7 were submitted with the supplemental submission
8 and the numbers were very small.

9 DR. BARDACH: Yes, we didn't submit it
10 by hospital. We didn't do individual hospital
11 performance measurement. It was just for the
12 group of kids in the younger age group. But
13 performance was quite low, yes.

14 CO-CHAIR SUSMAN: Okay, any other
15 questions about -- yes.

16 MEMBER BOST: I'm having trouble.
17 What were the denominators associated with the
18 rates that you are providing, the count of the
19 denominator? Because usually if it is less than
20 21, I tend to not even think it is worth looking
21 at.

22 DR. BARDACH: Yes, that makes sense.

1 So, it is provided in materials but I will read
2 it out loud.

3 Hospitals, overall, had 257 eligible
4 patients and then we just have them Hospitals A,
5 B, C, D, and E. Hospital A had 36 and a
6 performance of 25. Hospital B had 166 eligible
7 patients, performance level of 18. Hospital C
8 had 18 patients and 83 percent -- sorry -- a
9 hospital performance score of 83. And then
10 Hospital D had 22 eligible patients and a mean
11 performance of 66. Hospital E had eligible
12 patients of 15 and a mean of 40.

13 If you would like, I can read you the
14 confidence intervals.

15 MEMBER BOST: No, but it just sounds
16 like the first two are high enough, I think, to
17 consider. So, that does narrow the gap a little
18 bit.

19 CO-CHAIR SUSMAN: Any other questions
20 or comments? Okay, let's go ahead and consider
21 the vote on this one.

22 MS. CHAVEZ: So, we have increased the

1 time to vote to 30 seconds.

2 (Laughter.)

3 MS. CHAVEZ: Hopefully, there won't be
4 any more problems.

5 CO-CHAIR SUSMAN: When you get to
6 three days, let us know.

7 MS. CHAVEZ: And for Lauren and
8 Marlene on the phone, one is high; two, moderate;
9 three low; four, insufficient. And we are voting
10 on performance gap.

11 CO-CHAIR BROOKEY: So, is there any
12 harm in having everybody try to click it twice
13 during the 30 seconds?

14 MS. CHAVEZ: There shouldn't be.

15 CO-CHAIR BROOKEY: Can we try that,
16 just to see if we can get everybody in?

17 DR. NISHIMI: What we are going to do
18 is announce we only have 22, keep clicking.
19 Because we know that all the clickers are working
20 because we have had a vote where they all showed
21 up. So, it is clearly someone's is not quite
22 hitting it.

1 CO-CHAIR SUSMAN: Okay, Severa, are
2 you ready?

3 MS. CHAVEZ: Okay, ready, go.

4 CO-CHAIR SUSMAN: Go.

5 MS. CHAVEZ: Fifteen, twenty-three.
6 One more.

7 DR. NISHIMI: One more.

8 MS. CHAVEZ: Twenty-four. Ten seconds
9 left.

10 (Laughter.)

11 CO-CHAIR SUSMAN: First adherence.

12 MS. CHAVEZ: Okay, so two voted high;
13 eighteen voted moderate; three voted low; and one
14 voted insufficient.

15 CO-CHAIR SUSMAN: So, moderate carries
16 it and we will move forward.

17 Next is the quality construct, let's
18 see, and the issues of reliability and validity.
19 So, reliability, any key comments on this portion
20 of the measure? Are they consistent results?

21 Yes?

22 MEMBER BERGREN: Well, I just thought

1 it would be nice to work off of, is it Kevin, I
2 can't see your card --

3 CO-CHAIR SUSMAN: Thank you. Kevin
4 appreciates that.

5 MEMBER BERGREN: So, the reliability
6 was 100 percent but there were only four patients
7 sampled in the reliability but there weren't any
8 concerns with it either.

9 The validity testing was done via
10 consensus, face validity, through the Delphi
11 process. And the consensus was that if this is
12 performed, then that should result in high
13 quality.

14 There is believed to be meaningful
15 difference, based on whether or not the measure
16 is performed and the likelihood of missing data
17 is not likely. It is not likely that this would
18 be missing data because it is data that is
19 already captured in the chart.

20 CO-CHAIR SUSMAN: Okay, so we are
21 going to be considering the reliability first,
22 things like the statement of the numerator,

1 denominator, consistency of those results, what
2 sort of reliability testing was done.

3 Are there other comments or questions?
4 Let's do Kerri and then I will get over across
5 the way.

6 MEMBER FEI: Okay, thank you. My
7 question is about the denominator. And I just
8 wanted to make sure that I am clear and thinking
9 about this the right way.

10 The way it is stated here is that it
11 is patients 5 to 19 seen in the ED with psychotic
12 symptoms but it is really patients 5 to 19
13 discharged from the ED, could be to home, could
14 be to another setting of care. I find that to be
15 very confusing. And I get it. I think the
16 denominator could be reworked for public-facing
17 folks, so that they know every day people aren't
18 going to get that part.

19 So, if the denominator could be
20 restated to be reflective of what they are
21 actually measuring, the population you are
22 actually measuring for clarity purposes.

1 CO-CHAIR SUSMAN: Okay, across the
2 way.

3 MEMBER MOYER: The discomfort that I
4 am having, the measure of reliability seems to be
5 pretty good for the older kids. I'm very
6 uncomfortable that we have a whole bunch of -- we
7 have a chunk of patients for accountability and
8 we have people we actually haven't got the
9 vaguest idea whether this is reliable in that
10 younger age group.

11 And I'm trying to figure out where,
12 and Jeff, I think we need your guidance as to
13 where this fits in terms of our vote. I am not
14 going to be comfortable approving this measure as
15 it is currently stated.

16 CO-CHAIR SUSMAN: Well, remember at
17 the end we vote on the measure altogether. And
18 it is conceivable that it could squeak by and in
19 the end we would say it wasn't something that we
20 felt comfortable with going forward.

21 When there is a part of the population
22 that reliability testing has been performed

1 either very scantily or not at all, it is going
2 to question gee, we just can't say whether it is
3 reliable or not. And there are also, I think
4 with that, concerns about the evidence, as we
5 just discussed and concerns about the validity
6 because at least the face validity is much less.
7 And as we described from the measure perspective,
8 developer perspective themselves, this may not
9 have been the intended outcome with the age
10 range.

11 So, all, I think, important points
12 that might limit our enthusiasm for the measure.

13 MEMBER MOYER: I guess I just have a
14 concern if we vote positively -- I am sort of
15 voting on what I understand about the older age
16 group because it has a lot of positives. But in
17 the end, there is a chunk that we can't address.

18 DR. NISHIMI: I think you need to
19 weigh how you are going to vote. If it goes
20 down, it can be reconsidered. If it goes
21 forward, it can be reconsidered. I mean, so, but
22 it will be reconsidered if it goes down.

1 CO-CHAIR SUSMAN: I mean -- oh. You
2 are shaking your head. Obviously, there is
3 something there that bothers you.

4 DR. NISHIMI: During the comment
5 period, if you get all negative comments, let's
6 say, even though it has gone forward, then you
7 can reconsider it. If you voted down, the
8 developer has the opportunity to bring new
9 information forward and it gets reconsidered.

10 MEMBER MOYER: So, in any case, it can
11 be reconsidered.

12 DR. NISHIMI: Right. It is unlikely
13 to be reconsidered if all of the comments come in
14 positive and you put it forward.

15 CO-CHAIR SUSMAN: So, I mean this is
16 an iterative process. Once we go from here to
17 get the comments, there is consideration, and
18 then it goes to the bigger committee to be
19 considered. But we really need to do our jobs
20 well and with the best of our ability, given the
21 specification we have, which is the larger age
22 range, to decide where we go.

1 Let's go down to the end and then we
2 will come back up.

3 MEMBER BOST: I just wanted to
4 clarify. I don't think I heard it but besides
5 the percent agreement, there was also the
6 reported interclass correlation coefficient of
7 0.42 across the five hospitals, which is
8 considered high by reliability standards, again,
9 with the caveat that three of the hospitals had
10 pretty small denominators.

11 CO-CHAIR SUSMAN: Thank you. Okay.

12 MEMBER STANLEY: I have some concerns
13 about the denominator as well and concur with
14 what Kerri had said about public face of this
15 particular measure. But I am wondering if you
16 can tell us, is there any -- do you have any data
17 that shows, for example, the visits to the ED
18 where there are psychosis symptoms but yet at
19 discharge, there is not a psychotic diagnosis?
20 Because if you are carving out those who have
21 perceived psychotic symptoms but don't end up
22 with a diagnosis, is there a missed opportunity

1 there for testing?

2 CO-CHAIR SUSMAN: Go ahead.

3 DR. MANGIONE-SMITH: Yes, I would say
4 absolutely that is a missed opportunity for
5 testing. We were, unfortunately, limited to the
6 data sources we have to identify the population
7 and, given over two years in one of these
8 community hospitals, we only saw 15 cases and the
9 number of charts you would have to review to try
10 to find kids who had psychotic symptoms without a
11 diagnosis wouldn't be logistically feasible. I
12 wish there was some way to do that.

13 If we had EHRs in place where we could
14 troll for something that picks up psychotic
15 symptoms, rather than psychosis as a diagnosis,
16 absolutely, we would want to, I think, look at
17 those cases in the teenage age group. But, given
18 the data sources we have for specifying this
19 measure, it is not possible at this point in
20 time.

21 CO-CHAIR SUSMAN: David, did you have
22 another comment or --

1 MEMBER KELLER: Yes, I was thinking.
2 I was processing what you said and I had almost
3 forgotten what my question was. Just a process
4 question going forward.

5 When a measure is being reconsidered
6 at the follow-up phone call and the measure
7 developer is allowed -- I heard the language you
8 used Robyn was bring additional information to
9 the discussion -- is the measure developer
10 allowed to modify the measure being considered at
11 that time as well? Because that is different
12 than bringing additional information.

13 DR. NISHIMI: Yes, that would be
14 encompassed by that, if they modified the measure
15 and brought forth testing data to support that
16 measure. They can't modify the measure and not
17 bring you data to support it.

18 CO-CHAIR SUSMAN: I mean as it is,
19 from a practical standpoint, most of their data
20 is on the older age range anyway. So, the five
21 percent or what have you probably aren't going to
22 meaningfully change the testing data. Is that --

1 DR. MANGIONE-SMITH: So, that is just
2 about what I was about to offer to the group.
3 Given the workgroup call, we have actually
4 already redone all of the analyses just including
5 12- to 19-year-olds and the results are extremely
6 similar to what are in front of you today. And
7 you know, we would have no issue with
8 resubmitting it with that information.

9 CO-CHAIR SUSMAN: And just to chide
10 that we need to consider the broader age range
11 because that is what was submitted.

12 And Kevin.

13 MEMBER SLAVIN: So, my question just
14 has to do with the reliability related to the
15 coding part. And it kind of gets to Carol's
16 question about not having psychosis as the final
17 diagnosis. Since this only looks at the first
18 two diagnoses of somebody coming out of the ED
19 and it is possible, I guess the questions sort of
20 are is the intent if the patient has psychosis
21 and presents even with something else, they
22 should still be screened because they have a

1 known diagnosis of psychosis or is it really only
2 if they present with acute psychosis? And if
3 there is something that sort of takes precedence
4 over the psychosis reason for coming to the ED,
5 then psychosis very likely could fall to the
6 third or fourth diagnosis.

7 And this, again, all gets into coding
8 is really designed to maximize billing
9 opportunities as opposed to identify patients
10 with real problems.

11 So, is it worth thinking about
12 extending that diagnosis code further down or in
13 terms of missing some of those opportunities?

14 DR. BARDACH: So, just a point of
15 clarification for all these administrative
16 measures. So, it says in the specifications, it
17 uses lingo which I apologize for, it says a
18 primary or secondary diagnosis. But the
19 secondary diagnoses actually mean anything after
20 the primary one. So, it includes every single,
21 all diagnostic slots. And I apologize.

22 CO-CHAIR SUSMAN: Thank you for that

1 clarification.

2 David, did you have another question?

3 Okay, no problem.

4 Okay, anybody else have any questions
5 related to reliability?

6 And please vote on reliability alone
7 here. And are we trying to do the electronic
8 version?

9 ***PART 2 Section B***

10 MS. CHAVEZ: Yes. So, we are now
11 voting on reliability. Again, for those on the
12 phone, one for high; two, moderate; three, low;
13 four, insufficient. We are expecting 24 votes.
14 Ready, go.

15 Nineteen so far; twenty-three; twenty-
16 four.

17 Okay, so one voted high; thirteen
18 voted moderate; nine voted low; one insufficient.

19 CO-CHAIR SUSMAN: Okay. So, we go on
20 now to validity. And I think this is where many
21 people have had some questions about the
22 validity, particularly in our younger aged

1 patients.

2 So, Kevin, our go-to man on this
3 measure. We might as well go to you again.
4 Anything further about validity you would like to
5 call to our attention?

6 MEMBER SLAVIN: No, I think the
7 process for determining validity is the same as
8 the previous measure, which we talked about a
9 little bit, although, we didn't get that far in
10 the actual discussion. And it really comes down
11 to the validity for the age range, in my mind, at
12 least, the validity for the age range as
13 specified.

14 CO-CHAIR SUSMAN: And so as I
15 understand the validity of this measure is based
16 on the Delphi method, the recommended procedures
17 through some august bodies, which if we follow
18 that through, means that it is going to be either
19 a low or moderate degree of validity, by
20 definition.

21 DR. NISHIMI: Right. So, the highest
22 -- the eligible ratings are moderate, low, or

1 insufficient because it was only tested based on
2 face validity. So, it is not eligible even for
3 high under the NQF rubric.

4 CO-CHAIR SUSMAN: Questions further
5 about the validity? Yes, Kevin, you have a
6 comment.

7 MEMBER SLAVIN: Actually yes, it is
8 just procedural. Is this like the other measures
9 that if it is voted low, it would stop at this
10 point?

11 CO-CHAIR SUSMAN: That is my
12 understanding that this is a must-pass. Is that
13 correct?

14 DR. NISHIMI: Yes, it is must pass.

15 CO-CHAIR SUSMAN: So, low will get you
16 out; two, which is moderate; and then
17 insufficient, which is insufficient.

18 Any further comments? If not, let's
19 move on to voting on this. We are getting our
20 electronics in gear here.

21 MS. CHAVEZ: We are voting on
22 validity. Again, it is the same one for high;

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

2 Ready, go.

3 Fourteen, twenty-two, twenty-four.

4 Okay, so nobody voted high; nine
5 moderate; fifteen voted low; and zero
6 insufficient.

7 CO-CHAIR SUSMAN: So, just a
8 procedural question with the majority being low,
9 does that preclude further discussion?

10 DR. BURSTIN: In some ways,
11 particularly if there is an opportunity for
12 change post-comment, I just suggest the committee
13 finish up the remaining criteria, just so you
14 don't have to repeat it on a phone call, which is
15 always harder.

16 DR. NISHIMI: And I just want to
17 announce for the record that the vote on
18 reliability actually was in the gray zone, as
19 well but when it is in the gray zone, you
20 continue.

21 You have to be outside of 60 and
22 outside of 40.

1 CO-CHAIR SUSMAN: All right. So, we
2 are going to continue on at Helen's suggestion
3 and look at feasibility. Are there any concerns
4 about the feasibility, how this would actually
5 happen in practice? Any concerns from those who
6 closely reviewed? I didn't see any but I don't
7 want to give it short drift.

8 MS. CHAVEZ: No.

9 CO-CHAIR SUSMAN: Thank you. Well, if
10 we are ready, let's go ahead and vote on
11 feasibility.

12 MS. CHAVEZ: So, we are voting on
13 feasibility. One, high; two, moderate; three,
14 low; four, insufficient. Ready, go.

15 Twenty-two, twenty-three, twenty-four.

16 CO-CHAIR SUSMAN: All right. So, it
17 looks like this one is moderate or high, on
18 average.

19 MS. CHAVEZ: Eleven voted high, twelve
20 voted moderate, one voted low, zero voted
21 insufficient.

22 CO-CHAIR SUSMAN: Okay, usability and

1 use. So, is this currently in use? Is it
2 publicly reported? Has there been any
3 information? What are the unintended
4 consequences?

5 Any comments on usability?

6 MEMBER BERGREN: It is not currently
7 in use. And it is to be used for benchmarking
8 and quality improvement. And there were no
9 unintended consequences reported.

10 And I don't recall -- I did look at
11 the transcript of our phone discussion and didn't
12 find concerns with the usability.

13 CO-CHAIR SUSMAN: Would usability be
14 affected by the broad age range of this
15 population that is currently specified? Again,
16 it is a relatively small number of patients but
17 those kiddos were younger.

18 Ricardo.

19 MEMBER QUINONEZ: So, I have a
20 question for anyone if they can think of it
21 because I couldn't think of that looking at this
22 measure. What could be possible unintended

1 consequences from this measure? Because
2 especially looking at administrative data, right?
3 I mean the one I can think of is someone gets
4 labeled as a drug user and is not because, again,
5 it is not a very reliable test but you can't
6 really see that through administrative data.

7 CO-CHAIR SUSMAN: I will go over here.

8 MEMBER MORROW-GORTON: And actually,
9 you would probably look at it anyway because the
10 young children have a risk of getting into
11 somebody else's stuff like alcohol and whatnot.

12 So, this would be part of -- at least
13 in my mind, this would be part of the workup of
14 psychosis, even in a younger child presenting to
15 the ER.

16 CO-CHAIR SUSMAN: I guess the
17 unintended consequences, occasionally, could be
18 things like diverting resources from a high-
19 return, high-impact measurement an improvement
20 efforts versus ones that are much lower; the
21 excessive testing or use of resources.

22 Please.

1 DR. MANGIONE-SMITH: I just want to be
2 completely clear. Our intent was not to work up
3 causes of psychotic symptoms in the ED. It was
4 really to look for comorbid substance use among
5 people with psychosis.

6 CO-CHAIR SUSMAN: Kevin.

7 MEMBER SLAVIN: I mean, in my mind,
8 the unintended consequences really are kind of a
9 downstream effect. If you test more people and
10 you have a test that is unreliable, you may be
11 either incorrectly are labeling people early on
12 and if somebody has psychosis, it may affect
13 family dynamics. It may affect further treatment
14 where they are seeking care. If they are labeled
15 inappropriately, it also affects the false
16 negatives, in terms of missing people who may
17 definitely have an issue or problem.

18 So, the unintended consequences I
19 don't think are so much, in my mind, for testing.
20 In my region, you cannot admit somebody with any
21 mental health issue to anywhere without having a
22 drug screen done before they leave the ED to go

1 somewhere else. So, we already see this sort of
2 put into play. It is just the consequences of
3 having a test that has some unreliable results
4 and what it does at the local level to that
5 individual, as opposed to on a broader scale.

6 CO-CHAIR SUSMAN: Ricardo.

7 MEMBER QUINONEZ: And I agree with
8 you. Again, just the point that that probably
9 cannot be obtained from administrative data, that
10 level of consequences.

11 CO-CHAIR SUSMAN: Okay, thanks for
12 everybody's comments. Let's talk about usability
13 and use and go ahead and take our vote.

14 MS. CHAVEZ: Okay, for those on the
15 phone one, high; two, moderate; three, low; four,
16 insufficient. Ready, go.

17 Twenty-one votes; twenty-four.

18 So, three voted high; fifteen voted
19 moderate; five voted low; one voted insufficient
20 information.

21 CO-CHAIR SUSMAN: Okay. Now, given
22 our voted previously, do we need to vote on the

1 measure or not? Okay, so we are going to move to
2 overall suitability for endorsement. One is yes,
3 and two is no.

4 Any final comments on this? My only
5 observation is that truing up the age range on
6 this one would be relatively easy. And I would
7 feel, personally, more comfortable with it trued
8 up, rather than voting for suitability now.

9 Any other overall comments? Yes,
10 please.

11 MEMBER KELLER: Just, again, to make
12 sure I understand the procedure. So, at this
13 point, if we were to vote no at this time, then
14 it goes back to the measure developer and they
15 have the opportunity to bring back both
16 additional data and a revised measure for us to
17 consider at the follow-up phone call, at which
18 point we would change our vote.

19 DR. NISHIMI: Right. You are already
20 in the gray zone for reliability. So, it is
21 going to have to be addressed somehow.

22 MEMBER KELLER: And so we would have

1 to think about the reliability question and then
2 think about our total question, if this turns out
3 to be a no.

4 DR. NISHIMI: Yes.

5 CO-CHAIR BROOKEY: Well, just to add
6 to the confusion, whether you vote yes or no, it
7 still could be amended. If we have
8 recommendations for the age range to be changed,
9 it still could happen irrespective of the vote on
10 this particular questions.

11 DR. NISHIMI: Right.

12 MEMBER KELLER: Got you.

13 CO-CHAIR SUSMAN: Let's go ahead and
14 vote. We may want to give some feedback, say
15 through a straw vote thereafter, depending on how
16 this turns out. So, we have a one and a two.
17 Yes, is one; two is no. Severa.

18 MS. CHAVEZ: Okay, everyone ready?

19 Go.

20 Twenty-three. Okay, so six voted yes,
21 eighteen voted no.

22 CO-CHAIR SUSMAN: Then maybe just as

1 feedback by a show of hands, if the age range was
2 amended, as we have discussed to the older kids,
3 the adolescents, would that change your belief
4 around suitability for endorsement?

5 So, let's just have a show of hands
6 yes and no. If the age range were changed, would
7 you be more likely to vote in favor of this? And
8 those otherwise, no? Okay.

9 So, it looks like the age is one of
10 the specific and probably relatively easily
11 correctable.

12 Any other work? Do we need to ask for
13 comments or anything along that line? Okay.

14 Thank you very much. That was a,
15 again, very helpful discussion and feedback.

16 So, unfortunately, we have fallen a
17 bit behind but I'm sure this group will catch us
18 up, as we talk to 2807: Pediatric Danger to Self:
19 Discharge Communication with Outpatient Provider.

20 And any recusals on this one? Okay,
21 then, let's move forward to our measure
22 developer.

1 DR. BARDACH: Thanks.

2 CO-CHAIR SUSMAN: Guess who?

3 DR. BARDACH: Back again.

4 This measure is also a medical
5 records-based measure. Eligible patients were
6 children 5 to 19 years old who were admitted to
7 the hospital with dangerous self-harm or
8 suicidality.

9 The measure is the percentage of
10 eligible patients with documentation in the
11 hospital record of a phone or email discussion
12 between the inpatient and outpatient providers,
13 regarding the plan for follow-up. Communication
14 can occur anywhere between 24 hours prior to
15 discharge up to 48 hours after discharge.

16 Regarding a couple concerns from the
17 workgroup call, there was a concern about the
18 lack of evidence for this measure. Again, we
19 mentioned the difficulty in generating this
20 evidence, as well as pointing out that there is
21 strong clinical consensus on this measure in the
22 national guidelines from the UK that we cite, as

1 well as endorsement from our multi-stakeholder
2 Delphi panel.

3 In addition, there is randomized
4 control trial evidence from the literature on
5 inpatient to outpatient transitions that supports
6 this process measure for the larger population of
7 patients with complex conditions. We suggested
8 this literature and the studied processes of care
9 from this literature are generalizable to the
10 proposed subset of patients with complex chronic
11 mental health condition who are as much as, if
12 not more so, in need of care coordination and
13 successful transitions of care.

14 There was also a concern from one
15 member that communication would be unlikely to be
16 documented in the chart, if it had occurred, with
17 an implied concern the providers would not be
18 getting credit for doing this handoff.

19 A couple things in response to this
20 concern. There are certain aspects of care for
21 which lack of documentation is, in itself, an
22 indicator of poor quality. For instance, it is

1 standard of care to document a history and
2 physical and to document vital signs that are
3 taken during the course of care. The Delphi
4 panel felt strongly that a core aspect of
5 discharge care for a suicidal pediatric patient
6 was documentation of communication with a follow-
7 up provider. This type of warm handoff
8 communication will just not be as effective if it
9 is not documented was the thinking from the
10 Delphi panel.

11 And furthermore, from an operational
12 standpoint, we suggest that it will be relatively
13 straightforward to create a structured field for
14 this in an EMR to facilitate that documentation.

15 Lastly, there was a concern about the
16 exclusion from the measure of patients whose
17 outpatient psychiatrist works in the hospital's
18 outpatient clinic. So, this exclusion was
19 strongly supported and acknowledges the real
20 possibility that it was strongly supported by the
21 Delphi panel and it also acknowledges the real
22 possibility that a patient might be admitted

1 inpatient into a well-integrated inpatient and
2 outpatient system. For instance, in Kaiser or in
3 an inpatient facility with an outpatient follow-
4 up program, in which providers within the same
5 subspecialty group work closely together and it
6 would be much easier for an outpatient provider
7 to contact the inpatient provider and have access
8 to patient medical records from the
9 hospitalization.

10 Under these scenarios, the delivery
11 system design is facilitating the care
12 coordination that this measure otherwise would be
13 needed to instigate and, therefore, the exclusion
14 was decided to be included.

15 Again, we are happy to provide any
16 more details, as asked but those seem to be the
17 highest priority issues from the call.

18 CO-CHAIR SUSMAN: Thank you very much.
19 Let's turn to the primary reviewers, Jill, Tara,
20 and Craig.

21 MEMBER MORROW-GORTON: So, I get to be
22 on the hot seat, right?

1 CO-CHAIR SUSMAN: Yes, thank you.

2 MEMBER MORROW-GORTON: All right. As
3 we looked at this one, I think we all felt like
4 the warm handoff, the general studies that are
5 not specific to this population, so not kids with
6 harm, not always kids, but did show some evidence
7 that there was improved care. Most of this was
8 based on evidence -- or most of the evidence was
9 based on expert consensus and opinion through the
10 American Academy of Child and Adolescent
11 Psychiatry and the NIH, the National Institute
12 for Health and Care Excellence.

13 I think that when we looked at this,
14 we had the concerns about some of the exclusions
15 and the assumption that communication is better
16 within an institution than without. And there
17 also was a significant performance gap in terms
18 of very low rate of communication, which could
19 have been that it wasn't documented in the chart
20 but also could have been that it didn't happen.

21 Do you all want to add anything?

22 CO-CHAIR SUSMAN: Other comments?

1 MEMBER BRISTOL-ROUSE: I would just
2 add that this is, even though there isn't a lot
3 of evidence, as Jill said, for this specific
4 population that this is an extremely patient-
5 centered measure. So, while it may not be
6 translating into some clinical or financial
7 outcomes, that it is, across the board, important
8 to patients and families.

9 CO-CHAIR SUSMAN: Ricardo and then
10 David.

11 MEMBER QUINONEZ: So our hospital sees
12 75 percent Medicaid. That is our population.
13 And a large percent of those patients cannot
14 identify a primary care provider. And so that is
15 one problem that I see.

16 The other one is that communication
17 varies a lot. There has been a lot of
18 publications in the hospital medicine literature
19 about trying to standardize how we communicate
20 with outpatient providers. But one of the things
21 that we have learned is that it is incredibly
22 varied. And not only varied in the way the

1 hospital is communicating or the hospital
2 provider is communicating but the way the primary
3 care physicians want to have communication given
4 to them.

5 And so for example, we use various
6 methods and one of them is a patient portal that
7 some of our primary care clinics have access to,
8 in which we put out a discharge summary of the
9 patient and then they can access those records.
10 So that, while technically would not be
11 documented communication in the record, there was
12 very good handoff of patients.

13 And so those would be two of my main
14 concerns.

15 CO-CHAIR SUSMAN: Thank you. David.

16 MEMBER KELLER: So, you mentioned the
17 concern about the within the institution
18 communication problem, that exclusion, and I just
19 have to reecho that.

20 I, personally, worked in an
21 institution where the psych department decided to
22 blind all the rest of us to any encounter in the

1 psych department without telling us. So,
2 patients I knew were on psych meds all of a
3 sudden had no record of it. And I screamed and
4 they fixed it.

5 But I think there is an incredibly
6 wide misunderstanding of the rules regarding
7 confidentiality and psychiatric matters. And
8 that really interferes with this kind of
9 communication in a major way, both within
10 institutions and outside of institutions. And
11 I'm sorry to hear the Delphi panel thought it
12 wasn't a problem within institutions because I
13 absolutely think it is and am interested in their
14 evidence that that is not a problem, besides
15 their own experience.

16 CO-CHAIR SUSMAN: Well, I think by the
17 nature of the process, it is a Delphi panel. It
18 is, you know I think part of the question, again
19 for this, is this isn't high-quality evidence.
20 There aren't randomized control trials and it is
21 important to provide the feedback.

22 MEMBER KELLER: I mean I have worked

1 in three different systems in the last five years
2 and it has been a major problem in all three of
3 them in three different states. So, I just have
4 a hard time imagining that it wasn't perceived by
5 a group of experts.

6 CO-CHAIR SUSMAN: I'm going to go over
7 to Debbie.

8 MEMBER MILLER: Can I also get in
9 queue?

10 CO-CHAIR SUSMAN: Sure, go ahead.

11 MEMBER MILLER: Oh, sure, this is
12 Marlene. Yes, I was going to agree on that with
13 David about the inter-institutional issues. We
14 have some of those same issues of blinding the
15 data for confidentiality reasons. It makes it
16 difficult.

17 So, again, I would echo I'm surprised
18 that the committee, the Delphi group didn't
19 discuss it.

20 But I think the bigger issue with this
21 to me is the documentation and what that is.
22 Making sure that it is effective documentation

1 actually makes a difference. It is very hard in
2 these types of measures where you just say, you
3 can just put a sentence that I had this
4 communication. That doesn't mean it was heard or
5 you actually talked to the person or was it the
6 quality that actually impacted.

7 Again, I find myself, I agree with the
8 concept that there should be warm handoff but
9 anytime we break that down to a simple
10 documentation in a chart, usually all of that
11 richness that we are actually looking for gets
12 lost because of just the nuances of documenting
13 and auditing and that kind of stuff.

14 CO-CHAIR SUSMAN: Thank you very much.
15 Debbie.

16 MEMBER FATTORI: So, my comment was
17 very similar. Certainly handoffs and transitions
18 of care are critical junctures in the care of any
19 patients and this is a vulnerable group.

20 But I am wondering from the developers
21 how did you look at the patient record. How did
22 you find this? Because I know in my institution

1 it sometimes isn't documented or if it is, it is
2 buried in a progress note. So, how did your team
3 and your data collection deal with that issue?

4 CO-CHAIR SUSMAN: Why don't you
5 respond to that?

6 DR. MANGIONE-SMITH: Sure. So, at
7 each of the hospitals where this was field tested
8 we had nurse research abstractors who were very
9 familiar with that particular hospital's charting
10 system and went through a training about what we
11 would count as a documentation of a warm handoff.
12 And to Marlene's point, we are pretty lenient.
13 If they say Dr. So-and-So was called, follow-up
14 plan discussed and that is all they wrote, that
15 was given credit.

16 I mean so it was, in my view, a
17 relatively low bar of documentation we were
18 asking them to look at but they were quite
19 familiar with their own hospital's charting
20 system and I would hope would have known to look
21 for this sort of information.

22 CO-CHAIR SUSMAN: Thank you. Kevin.

1 MEMBER AGORATUS: This is Lauren. I
2 also have a question when you get a chance.

3 CO-CHAIR SUSMAN: Go ahead, Lauren.

4 MEMBER AGORATUS: Okay, thank you.
5 Sorry, it is hard because I am not there to raise
6 my hand or anything.

7 CO-CHAIR SUSMAN: Yes.

8 MEMBER AGORATUS: I agree with the
9 conversation that this is an extremely important
10 measure. I also agree with the comments
11 regarding the confidentiality issues. I am
12 wondering how this dovetails with minor consent
13 to mental health treatment because, again, in
14 some states, that could be as young as 16, even
15 14. So, I don't know if that is a question for
16 the developers.

17 I actually heard from families who
18 have begged to have the child stay and the child
19 has convinced everyone they are fine and then
20 they go home and commit suicide.

21 So, I guess that is my concern is the
22 minor consent issue.

1 CO-CHAIR SUSMAN: Do you want to
2 respond as developers?

3 DR. MANGIONE-SMITH: So for this
4 particular measure, to me it would seem even more
5 important that that handoff occur if the scenario
6 occurred that you just outlined. If a child has
7 convinced everybody they are ready to go and they
8 really aren't, I would hope that outpatient
9 follow-up had been a warm handoff. But this
10 wouldn't get into confidentiality of their
11 parents seeing anything because the measure
12 really doesn't address the parents being shared
13 this information, necessarily.

14 CO-CHAIR SUSMAN: Kevin.

15 MEMBER SLAVIN: I just had a couple of
16 questions about the abstraction process. I guess
17 the questions really are who would be responsible
18 for documenting. Does it have to be a physician
19 or if it is, I hate the term, but a physician
20 extender, a licensed clinical social worker, what
21 the ongoing treatment plan is, would they be
22 acceptable as far as the documentation? And I

1 think it has already been mentioned that just
2 because somebody says I spoke with so-and-so
3 doesn't necessarily guarantee that the quality of
4 the discussion and that the information has been
5 received on the other side.

6 And then I had a question about the
7 exceptions. And this is going to sound really
8 bad but in the area where I practice and this is,
9 again, dealing with mostly medical stuff, we have
10 large group practices where one physician rounds
11 in the hospital, the patient is followed by
12 technically the same group and the same set of
13 providers in a different office, and a lot of
14 times the ongoing care plan is not discussed
15 between people in the same group.

16 So, I had some concerns about the
17 exception for, and wanted some clarification on
18 the exception for same practice, same physician,
19 same group. Because when you are talking about
20 that kind of communication, if somebody is going
21 to a different office that is ten miles away and
22 nobody has spoken with each other, they may still

1 be considered to be excluded from that when in
2 actuality, the discussion hasn't really occurred
3 with the person who is going to do the follow-up.

4 DR. BARDACH: So, the abstraction
5 instructions, just in terms of who that person
6 is, they are instructed to say the hospital,
7 indicate one of the hospital providers
8 communicated by telephone or email with a follow-
9 up provider, which is either a PCP or a
10 psychiatrist.

11 So, it is relatively nonspecific but
12 focusing on the idea that it is somebody who is
13 part of the care team who is communicating with
14 the follow-up provider.

15 DR. MANGIONE-SMITH: So, I know there
16 is a lot of angst around sort of letting people
17 off the hook if it was what was considered an
18 integrated system by the people on the Delphi
19 panel but the problem was is that we had a person
20 on the panel who said so you mean to tell me that
21 if I saw this kid and took care of them as their
22 psychiatrist in the inpatient setting, and I am

1 the one they are following up with, I have to get
2 in contact with myself to get credit. So, that
3 was the genesis of this exclusion.

4 To be completely honest with you, we
5 were going to say it didn't matter if you were in
6 the same system, that some kind of handoff had to
7 occur with whoever was following you outpatient.

8 And I imagine that we could have
9 written it more strictly saying you were only
10 excluded if it was the same provider and maybe
11 that is what we should have done, rather than
12 saying provider or provider in the same
13 institution. But it is what it is.

14 CO-CHAIR SUSMAN: Okay, so let's go
15 down this side. Carol.

16 MEMBER STANLEY: So, can you talk in a
17 little more detail about what you could as a
18 numerator hit? So, if the hospital were to just
19 fax over some notes or evidence of what has
20 happened and it lands in a physician office fax
21 and someone picks it up, I mean with the
22 algorithm, where did you accept -- what did you

1 specifically accept as numerator hits?

2 DR. BARDACH: Thank you for the
3 question for clarification. We actually had a
4 big discussion about whether fax was acceptable
5 or not and it was decided it was not acceptable.
6 So, it is not included in the abstraction
7 instructions. It had to be telephone or email.

8 MEMBER STANLEY: So, if anybody from
9 the hospital made the phone call and talked to
10 anybody at the physician office, that would
11 count?

12 DR. BARDACH: Yes, the PCP or
13 psychiatrist follow-up provider was the --
14 anybody in the hospital, the hospital provider on
15 the care team for the patient making a phone call
16 or an email to the outpatient PCP or psychiatrist
17 who would be following up.

18 MEMBER STANLEY: So, does there have
19 to be evidence that an actual clinician spoke
20 with an actual clinician on each end?

21 DR. BARDACH: So the abstraction tool
22 says indicate one if the hospital provider

1 communicated by telephone or email with the
2 follow-up provider, PCP, or psychiatrist during
3 the time window of 24 hours prior to discharge or
4 48 hours after discharge.

5 So, I think you want it to have been
6 more -- you want to be able to say exactly what
7 the definition was the abstractors were
8 instructed to pay attention, mostly clinician,
9 care team providers.

10 MEMBER STANLEY: Okay.

11 DR. BARDACH: Does that help?

12 DR. MANGIONE-SMITH: Just to be clear,
13 we were not specific about who on the care team
14 in the inpatient setting had to make the handoff
15 but it did have to go to either a PCP or
16 psychiatrist. So, they couldn't simply call say
17 a nurse at the follow-up office and do the
18 handoff to the nurse. It did have to be either a
19 PCP or a psychiatrist.

20 And one other quick thing I wanted to
21 address with Ricardo, the other thing that we
22 require is that if the child did not have an

1 identified follow-up provider, we hold them
2 culpable for having identified one prior to
3 discharge in communicating with that person.

4 CO-CHAIR SUSMAN: Jon.

5 MEMBER FINKELSTEIN: So, one quick
6 thing. It is funny to me that we allow email but
7 not fax, if we don't say that the criterion is
8 someone had to respond to the email. Just
9 sending an email isn't very warm.

10 (Laughter.)

11 MEMBER FINKELSTEIN: But almost more
12 important is we are coming to this on several
13 measures, and I knew we would, the idea that the
14 measure doesn't cast a wide enough net. That in
15 one case, it should be internal systems that have
16 had communication as well.

17 I think for many of these measures
18 what is important, especially given the state of
19 evidence in pediatrics, the diversity of health
20 systems, especially for these mental health
21 conditions for kids, we are going to have to be
22 narrow enough so that for accountability when we

1 are measuring something, we know exactly what we
2 are measuring, even if there are things outside
3 those borders that would also be really
4 important. No one is saying they are not
5 important. No one is saying within system
6 communication isn't a big problem. It is. But
7 we might not be able to hold every system
8 accountable in the same way for things outside
9 those narrow borders. And I think the
10 performance is low enough that we have room to
11 move even in the narrow scope.

12 CO-CHAIR SUSMAN: So, I don't want to
13 cut off discussion but I also would like to
14 remind us we have a full group of measures. So,
15 for those of you who have your cards up, we will
16 get to you. Please make your comments quickly
17 and let's not repeat.

18 So, with that, Virginia.

19 MEMBER MOYER: I think that I have a
20 similar to Jon's except I have the opposite
21 conclusion from the same data, which is that I
22 think this is clearly one of the most important

1 things we can do for patients is to make sure
2 that they get appropriate follow-up and that the
3 information be there. But our ability to measure
4 whether that has happened, it seems to me, is
5 extremely poor.

6 And so we exclude email when we send
7 all our faxes by email. So, our fax would count
8 because our fax goes by email. And so the
9 measure -- the problem isn't that that was a bad
10 decision, it is that it is almost impossible to
11 make a good decision about how to measure the
12 issue of a warm handoff.

13 CO-CHAIR SUSMAN: Okay, down the line.

14 MEMBER BOST: The discussion that I
15 have heard is not necessarily about the
16 appropriateness of the numerator and denominator
17 but about the information not being documented
18 appropriately to actually calculate this rate.

19 But the developers have said that they
20 believe that is also an important contribution to
21 bringing this measure forward and I would just
22 tell folks to think about that when making --

1 whether that is appropriate or not when making
2 the decisions about evidence.

3 CO-CHAIR SUSMAN: Okay. And just
4 remember, we are voting on evidence here.

5 Debbie, did you have another comment
6 or are you okay? We'll give you that one.

7 CO-CHAIR SUSMAN: Any other comments?
8 Hearing none, let's move on to the vote about
9 evidence.

10 MS. CHAVEZ: Okay, we are now getting
11 ready to vote on evidence for Measure 2807:
12 Pediatric Danger to Self: Discharge Communication
13 with Outpatient Provider.

14 And for those on the phone, the
15 choices are one for high; two, moderate; three,
16 low; four, insufficient.

17 We are expecting 25 votes for this
18 measure and we have 30 seconds. Okay, ready?
19 Go.

20 Twenty-one, twenty-two, twenty-four.
21 One more.

22 CO-CHAIR SUSMAN: Jeff, are you

1 recused on this one or not? You are recused.

2 Thank you.

3 MS. CHAVEZ: Okay.

4 CO-CHAIR SUSMAN: Do you want to go
5 over to the park for a while, take in the
6 Washington Monument?

7 MS. CHAVEZ: Okay, so seven voted
8 moderate; eight voted low; nine voted
9 insufficient.

10 CO-CHAIR SUSMAN: So, great developers
11 in the cloud, what does this mean to us? Gray
12 zone?

13 I mean three and four -- three would
14 not move us forward. I mean seven --

15 DR. NISHIMI: It doesn't move forward
16 but with nine, they could consider an exception.

17 CO-CHAIR SUSMAN: I guess I am having
18 a hard time interpreting how you determine gray
19 zone and whether it goes forward or whether
20 because it is low and insufficient, we need to
21 consider an insufficient with exception vote. It
22 is more of a process.

1 DR. BURSTIN: The measure did not pass
2 on evidence. It is like 70 percent against. But
3 your next decision would be determine whether
4 this is a measure you would like to potentially
5 consider for exception.

6 CO-CHAIR SUSMAN: Okay. So, clarified
7 now, we are going to have the vote about
8 insufficient with exception. Remember, that is
9 based on a preponderance of evidence being or the
10 thought being that this would be a positive
11 thing, there wouldn't be unintended consequences.
12 One being insufficient evidence with exception
13 and two, no exception.

14 MS. CHAVEZ: Okay, read.

15 Fifteen, twenty-two. One more.

16 CO-CHAIR SUSMAN: Keep voting.

17 MS. CHAVEZ: Twenty-four.

18 So, 14 voted for insufficient evidence
19 with exception and 10 voted for no exception.

20 CO-CHAIR SUSMAN: Okay, so I guess
21 that is another gray zone. We continue on
22 forward. Let's see if we can pick up the pace

1 and go for opportunity for improvement or gap.

2 So, is there evidence for gap in this
3 measure? Okay, yes.

4 MEMBER KNUDSEN: Yes, there is. They
5 provided some performance results for this
6 measure using some data N of 177 over two years,
7 three hospitals and only 20.5 percent of the
8 hospitals actually recorded this happening. So,
9 that is a significant gap.

10 MEMBER KNUDSEN: There were no
11 statistical differences in terms of disparities
12 when they looked at this as well.

13 CO-CHAIR SUSMAN: Thank you.
14 Virginia, did you have a comment? No. Okay.

15 Any other discussion about gap? If
16 not let's turn to voting on gap.

17 MS. CHAVEZ: Again, one for high; two,
18 moderate; three, low; four, insufficient. Ready,
19 go.

20 Nineteen. We have twenty-one, twenty-
21 two.

22 CO-CHAIR SUSMAN: Someone has probably

1 got no battery.

2 MS. CHAVEZ: Twenty-three. One more.
3 Three seconds. Okay.

4 So, nine voted high, thirteen
5 moderate, and one voted low.

6 CO-CHAIR SUSMAN: Reliability testing.
7 Comments from our primary reviewers about
8 reliability of this measure?

9 MEMBER MORROW-GORTON: So, I think the
10 reliability testing they did in rate of
11 reliability had a high kappa and an ICC testing
12 at the hospital level that was also relatively
13 high. And there were 117 records, so it was a
14 fair number of records that were looked at.

15 So, I think we thought it was fairly
16 reliable.

17 CO-CHAIR SUSMAN: Okay, any more
18 comments about reliability? Kerri.

19 MEMBER FEI: I have another
20 denominator question. Earlier, the denominator
21 said it was patients discharged for self-harm.
22 Is it actually they are admitted for a self-harm

1 or suicide diagnosis and then subsequently
2 discharged after treatment?

3 DR. MANGIONE-SMITH: Right, so the
4 denominator population is identified using E
5 codes and V codes for suicidality.

6 MEMBER FEI: Okay. All right, thank
7 you.

8 CO-CHAIR SUSMAN: Okay, unless there
9 are other comments about reliability, let's move
10 to vote.

11 MS. CHAVEZ: Okay, voting on
12 reliability for Measure 2807. Ready, go.

13 Twenty, twenty-two, twenty-three.
14 Thank you.

15 Okay, six voted high, fifteen voted
16 moderate, three voted low, and zero for
17 insufficient.

18 CO-CHAIR SUSMAN: So, moving on to
19 validity. I think we have talked a lot about
20 validity overall. Anything new to say or bring
21 up specifically?

22 MEMBER KNUDSEN: I think that it is

1 important to note that there were no statistical
2 significant differences between those meeting or
3 those failing the measure in readmissions or ED
4 visits. So, I think that is really important.

5 CO-CHAIR SUSMAN: Okay, any other
6 comments? Kevin did you have one?

7 MEMBER SLAVIN: And I'm not sure how
8 other institutions work but one of the things I
9 think that may affect the validity is at what
10 point after discharge does the hospital close the
11 EHR for documentation purposes. Because if you
12 are allowed up to 48 hours after somebody is
13 discharged to send off and to document but if the
14 hospital closes the EHR before then so that they
15 can get the coding and billing done as quickly as
16 possible, documenting that is going to be
17 difficult.

18 CO-CHAIR SUSMAN: Please.

19 MEMBER MORROW-GORTON: I think in our
20 small group discussion, we also had a discussion
21 about the kids that left AMA. And given that
22 they were in the hospital for danger to

1 themselves or suicide, that excluding them from
2 this might be problematic as well.

3 CO-CHAIR SUSMAN: Thank you. Any
4 further validity questions?

5 Let's move forward, then, to vote.

6 DR. BARDACH: Can I?

7 CO-CHAIR SUSMAN: Oh, yes, please.

8 DR. BARDACH: I was just going to
9 offer one piece of information, which is that in
10 our testing there were zero people who met that
11 exclusion of leaving AMA.

12 CO-CHAIR SUSMAN: Thank you. Okay,
13 voting on validity.

14 MS. CHAVEZ: You are voting on
15 validity, one, two, three, four options.

16 Eighteen, twenty-two, twenty-four.

17 So, 12 voted on moderate and 12 voted
18 on low.

19 CO-CHAIR SUSMAN: So, I guess that is
20 gray zone again. And we will proceed on.

21 So, let's go ahead to feasibility. Is
22 this easily collectable data? Is it feasible to

1 get the measurement? Any measurement concerns?

2 Yes, so Virginia.

3 MEMBER MOYER: This is for the
4 developers. You used pretty well-trained nurse
5 extractors. I looked at this and I looked at all
6 the questionnaire and everything and I wondered
7 how challenging this would be in the setting of
8 not well-trained nurse abstractors, but people
9 who perhaps a little less well-trained. How
10 usable is this outside of that? Did you do
11 anything with that, with evaluating how hard it
12 was to train them?

13 DR. MANGIONE-SMITH: So, the feedback
14 we got, with the caveat that they are all
15 experienced abstractors was that the tool we
16 designed, the electronic data collection tool was
17 actually quite easy to use.

18 The person who designs the tool to
19 collect the information specifically designs it
20 so that abstractors don't have to think very hard
21 and they never have to make a subjective
22 judgment. So, and many times they don't even

1 know what measure the data they are putting in is
2 feeding into. So, and I think the average
3 abstraction time, I don't know if you have that
4 recorded down, but for the entire tool, which
5 collected many more measure than just this one,
6 was well under an hour. It was more like 30
7 minutes to collect the data for several different
8 measures.

9 So, our feedback was that it was quite
10 user friendly and easy to use. But again, in the
11 hands of somebody who is less experienced, I
12 don't know the answer to that, obviously.

13 MEMBER BOST: -- what percent were
14 required reviewing the notes by the trained nurse
15 versus actually being able to collect?

16 DR. MANGIONE-SMITH: So, I know for a
17 fact in two of the hospitals there was a
18 designated field. They could look for whether
19 there was documentation of a call to the follow-
20 up provider. But in three of the hospitals I
21 don't know whether they had to actually look into
22 notes or not. It is possible that they did.

1 CO-CHAIR SUSMAN: Okay, any other
2 questions about feasibility? If not, let's vote.

3 MS. CHAVEZ: Voting on feasibility.
4 One, high; two, moderate; three, low; four,
5 insufficient. Go.

6 Nineteen, twenty-two, twenty-three,
7 twenty-four.

8 Zero voted high, 12 voted moderate, 12
9 voted low, zero voted insufficient.

10 CO-CHAIR SUSMAN: This is a tale of
11 gray today.

12 All right, let's move on to usability.
13 Any questions about usability? This is not
14 currently in use?

15 Kevin.

16 MEMBER SLAVIN: Just in terms of the
17 types of communication that are allowed and HIPAA
18 compliance. I'm not sure -- you know email is
19 allowed. Not all email is secure. So, there is
20 some concerns about accessibility to information,
21 depending on how it is communicated.

22 CO-CHAIR SUSMAN: John.

1 CO-CHAIR BROOKEY: I just want to make
2 a comment about so we have a lot of electronic
3 processes, one of which is putting in default
4 items and smart sets and smart phrases. And a
5 measure like this could potentially allow
6 somebody to put in the right phrase, pulling it
7 into a smart set without actually having not done
8 anything related to what they said.

9 So, I just wanted to say that pulling
10 the data out maybe problematic, even in an EHR.

11 CO-CHAIR SUSMAN: Carol.

12 MEMBER STANLEY: Can you talk a little
13 bit about -- when I look at potentially using
14 this measure, to me it is more of a notification,
15 a measure of notification and not really a warm
16 handoff. Can you explain how you decipher
17 between a warm handoff and just a notification?

18 DR. MANGIONE-SMITH: So, to me
19 notification would be more like the fax being
20 sent or a discharge summary being sent to an
21 outpatient provider. A warm handoff, at least
22 the way we operationalized it was there need to

1 be a conversation either by email, which
2 certainly there could be concerns about security
3 where that is concerned for confidentiality
4 reasons, or a documented telephone call.

5 CO-CHAIR SUSMAN: Virginia, did you
6 have a question? No, okay.

7 Any others on usability? Let's go
8 ahead and vote.

9 MS. CHAVEZ: Voting on usability.
10 One, high; two, moderate; three, low; four,
11 insufficient. Go.

12 Twenty-one, twenty-four.

13 One voted high, ten voted moderate,
14 twelve voted low, one voted insufficient.

15 CO-CHAIR SUSMAN: Okay, still a split
16 here.

17 And let's go ahead and vote on the
18 measure. If there is other comments, final
19 comments, anything additional to add.

20 Okay, so this is an up/down. One,
21 yes; two, no.

22 MS. CHAVEZ: We are now voting on

1 Measure 2807, acceptability for endorsement.

2 Ready, go.

3 Twenty, twenty-two, twenty-three,
4 twenty-four.

5 Ten voted yes and fourteen voted no.

6 CO-CHAIR SUSMAN: Okay, again, very
7 close.

8 Any comments or suggestions to the
9 developer here? Yes, please, Dave.

10 MEMBER EINZIG: So, it just kind of
11 feels like sort of a clunky measure. It reminds
12 me of driving a car with square wheels, in a way.
13 I mean it kind of gets you there but it is not
14 going to work right. You know just kind of a
15 bigger picture of until we get a universal
16 healthcare record, I mean it is just going to be
17 kind of clunky along the way until we get there.

18 CO-CHAIR SUSMAN: Other feedback? Is
19 this something you would want to see in some
20 revised form? And if so, what would it look
21 like?

22 MEMBER MILLER: This is Marlene. I

1 would just encourage the developers to really
2 think about what documentation means, both what
3 is acceptable and what has to be in it so that it
4 is actually more likely a meaningful
5 conversation, a meaningful handoff and not just
6 the smart phrase comments. What really struck
7 home with me is how easy this would be to almost
8 game with a smart phrase.

9 CO-CHAIR SUSMAN: I think the
10 handoffs, internally, at least for me, would be
11 important to incorporate. I think the exception
12 that you were trying to get to wasn't handled as
13 artfully as it might be.

14 Any other comments to the developer?
15 Okay, we now have time to ask for
16 public comment. Robyn, do you want to?

17 DR. NISHIMI: Right. So, if there is
18 anyone here on-site or, operator, if there is
19 anyone on the line who wants to give public
20 comment.

21 OPERATOR: Okay, at this time, if you
22 had wanted to make a comment, please press * then

1 the number 1 on your telephone keypad.

2 There are no public comments from the
3 phone line.

4 CO-CHAIR SUSMAN: Okay. Well, this
5 has been a lot of work. I appreciate very much
6 the efforts of our measure developers. This was
7 a yeoman's work, so to speak. And I hope we see
8 revised measures coming to us.

9 Certainly, the ideas that are being
10 incorporated are certainly the direction. And
11 for a variety of reasons, it is very difficult in
12 this area to come up with really a well-tested,
13 valid, evidence-based measure. So, don't get
14 discouraged.

15 All right, this brings us to lunch.
16 And I'm not sure. Do we intend to have a working
17 lunch or how do you all suggest we go forward?
18 Okay, it is up to us.

19 We are behind by one measure. So, why
20 don't we -- it's about ten after. Why don't we
21 take about a 15-minute break to get started and
22 then about 25, 30 after, I am going to ask that

1 we reconvene and get ourselves going, try to get
2 back caught up.

3 So, thank you.

4 (Whereupon, the above-entitled matter
5 went off the record at 12:08 p.m. and resumed at
6 12:31 p.m.)

7 CO-CHAIR SUSMAN: The first of the
8 ADHD measures is 2817, accurate, ADHD diagnosis
9 from AHRQ, CMS, and I guess God or someone else.
10 And we'll start out with any recusals. Okay,
11 hearing none, let's turn it over for a brief
12 explanation from our developers.

13 DR. WOODS: So statistics provided by
14 the CDC, 5 million children between the ages of 4
15 and 17 have been diagnosed with ADHD. This is
16 increasing and the rates of ADHD diagnosis
17 increased 5.5 percent per year from 2003 to 2007.
18 Validated tools based on DSM criteria have
19 demonstrated effectiveness for diagnosing ADHD --
20 for distinguishing ADHD from the diagnosis of
21 other conditions. When less rigorous methods are
22 applied to the diagnosis of ADHD, the positive

1 existence of the condition may be missed, leading
2 to potential social and academic struggle.

3 In November of 2011, the American
4 Academy of Pediatrics published a new evidence-
5 based guideline for ADHD diagnosis follow-up and
6 treatment based on extensive review of the
7 existing evidence. One recommendation with a
8 high level of evidence indicated that when
9 diagnosing ADHD in children 4 to 18 years of age,
10 primary care clinicians should determine the DSM
11 criteria have been met, including documentation
12 of impairment in more than one major setting,
13 with information obtained from reports of parents
14 or guardians, teachers, other school mental
15 health clinicians involved in the child's care.

16 To make a diagnosis of ADHD -- so
17 there is a -- this new guideline and there are
18 several recommendations within this guideline,
19 this guideline recommendation is, and I'm reading
20 verbatim, "to make a diagnosis of ADHD, the
21 primary care clinician should determine that
22 Diagnostic and Statistical Manual of Mental

1 Disorders criteria have been met, including
2 documentation of impairment in more than one
3 major setting. The information should be
4 obtained primarily from reports, from parents or
5 guardians and teachers and other school and
6 mental health clinicians involved in the child's
7 care. The primary care clinician should also
8 rule out any alternative cause."

9 The evidence is grade B with strong
10 recommendations which is defined as RCTs or
11 diagnostic studies with minor limitations,
12 overwhelmingly consistent evidence from
13 observational studies. This level of evidence is
14 based on high to moderate quality scientific
15 evidence and preponderance of the benefit over
16 the harm.

17 The gaps in care include that -- a
18 survey done by the APA regarding the guideline,
19 91.5 percent of physicians were familiar with the
20 guideline recommendations. However, an
21 additional study found that approximately 50
22 percent of children with ADHD seen in practice

1 settings obtained care that matches the
2 guidelines of the American Academy of Pediatrics.

3 The pathway between the process
4 measure on the outcome, ADHD diagnosis increases
5 appropriate treatment, decreases inappropriate
6 treatment, improves quality of life and improves
7 care. In order to work on a measure in this
8 space, we engaged a technical expert panel, 25
9 experts and stakeholders that included
10 psychiatrists, psychologists, nurses, school
11 nurses, school psychologists, pediatricians,
12 developmental pediatricians, social workers --
13 did I say developmental pediatricians -- also
14 parent and patient stakeholders, other school
15 stakeholders. And this particular recommendation
16 stuck out to this group as something that would
17 be very impactful in the lives of children to
18 make sure that an accurate diagnosis is made
19 according to the appropriate criteria.

20 There are validated tools that use the
21 DSM criteria, so they recommended that the
22 measure look at validated tools or actual direct

1 assessment of the criteria through reports given
2 to the physician.

3 The measure itself -- the denominator
4 criteria are all patients aged 4 through 18 with
5 a diagnosis of ADHD. And the numerator criteria
6 are patients whose diagnosis of ADHD was based on
7 a clinical exam with a physician or other health
8 professional as appropriate, which includes
9 confirmation of functional impairment in two or
10 more settings and assessment of core symptoms of
11 ADHD including inattention, hyperactivity, and
12 impulsivity either through use of validated
13 diagnostic tool, based on DSM-IV criteria or for
14 ADHD through direct assessment of the patient.

15 We tested this measure as a chart
16 review measure in the primary care networks of
17 four hospitals in the Chicago area, a teaching
18 hospital, two safety net hospitals, and a
19 suburban hospital. And we also from that testing
20 worked with the American Board of Pediatrics and
21 they have incorporated the specification of this
22 measure into their maintenance of certification

1 Part 4 payment program. And since then, 313
2 physicians have used this measure as a measure
3 for improvement which they generally have to do
4 100 pre- and 100 post- actual patients.

5 Should I respond to the questions
6 here, too? There were a couple of questions
7 unresolved at the end of the conversation.

8 CO-CHAIR SUSMAN: Why don't you try to
9 hurry it up so --

10 DR. WOODS: Okay, I just wanted to
11 know if I should give you everything right now?

12 CO-CHAIR SUSMAN: No.

13 DR. WOODS: Okay.

14 CO-CHAIR SUSMAN: I really appreciate
15 it, but given the pressures of time, I'm going to
16 turn to our group of -- Martha, were you on --

17 DR. WOODS: Can I say one more thing,
18 just one more thing?

19 CO-CHAIR SUSMAN: One more thing,
20 okay. We'll let you -- one more.

21 DR. WOODS: That these measures were
22 also vetted through a public comment period where

1 we did active recruitment of comment.

2 CO-CHAIR SUSMAN: Thank you. Sounds
3 like it was very thorough.

4 Martha?

5 MEMBER BERGREN: So the call that we
6 had did think that the people on the phone did
7 believe that this was a very important measure,
8 but there was a lot of discussion about the
9 measure and almost every component of the
10 measure. So the reason that it's so important,
11 just to echo what you said is the implications of
12 false negatives and false positives. Both have
13 significant implications for the children that
14 are either diagnosed correctly -- incorrectly, or
15 not diagnosed when the diagnosis is present.

16 So one of the --- there were a ton of
17 issues with the numerator with many of the people
18 on the call believing that having actual
19 disagreement with the DSM criteria that perhaps
20 not all three symptoms are needed to have ADHD
21 and the implications of that on what the results
22 would be.

1 I want to make it clear that there was
2 a lot of discussion about what constituted
3 meeting the numerator. It can be either using a
4 validated tool for the symptoms or using direct
5 clinical assessment where the DSM criteria are
6 used to basically evaluate those same criteria.

7 And then the denominator is all
8 children between 4 and 18 years old with a
9 diagnosis of ADHD. And the diagnosis has to have
10 been within the previous year from the visit. So
11 the evidence is a recommendation and as you said,
12 it's grade B evidence, based on RCTs and
13 diagnostic studies and graded as strong.

14 The performance gap is present and
15 there is a performance gap within ethnicities
16 with 55 percent of African-American and Hispanic
17 patients meeting the criteria compared to 81
18 percent of white patients.

19 For the reliability, I don't see my
20 notes on the reliability.

21 DR. NISHIMI: We can just discuss that
22 when we get to the reliability section.

1 MEMBER BERGREN: Sure. Okay.

2 CO-CHAIR SUSMAN: Any other major
3 points for the committee?

4 MEMBER BERGREN: Oh, I'm sorry, do you
5 mean the other people?

6 CO-CHAIR SUSMAN: No.

7 MEMBER KELLER: The concern about
8 reliability was that reliability testing had only
9 been done on the numerator portion of the measure
10 and we were wondering why there had been no
11 reliability -- we didn't see reliability testing
12 of the denominator.

13 DR. WOODS: We did do reliability
14 testing of the denominator -- that diagnosis. In
15 order -- we pulled charts and then assured that
16 the diagnosis was present in the chart. And we
17 excluded then any -- actually, I guess you're
18 right. We didn't present how many we excluded.
19 We didn't exclude many, but we did exclude some.

20 MEMBER KELLER: It was a concern. We
21 were wondering why we hadn't -- we didn't see
22 that data.

1 DR. WOODS: We can get that for you,
2 but we didn't know you were interested in it.

3 CO-CHAIR SUSMAN: Okay, any other
4 major comments overall from those who reviewed
5 this closely?

6 Well, then let's go ahead and
7 concentrate on evidence. This is a process
8 measure. It has gone through systematic reviews,
9 some RCTs linking process with the outcomes of
10 note. Any questions, comments?

11 I know you've indicated, Martha, some
12 of the concerns about specification. We probably
13 are not going to rewrite DSM IV or V at this
14 committee meeting, so take it for what it's
15 worth. It must be the post-prandial slump.

16 MEMBER KELLER: I'll jump in. I think
17 the biggest concern in the numerator statement
18 was the clinical exam with a physician or other
19 healthcare professional because it just seemed
20 relatively straight forward to document and to
21 count what measure -- what standardized tools
22 were used. If you're using a Vanderbilt, you can

1 find a Vanderbilt in there. But it wasn't clear
2 to us exactly what counted as a clinical exam
3 with a physician that would be adequate for the
4 diagnosis of ADHD having done a number of --
5 having seen a lot of external records sent to me
6 from kids who have been diagnosed by other
7 physicians. Because I manage ADHD a lot in my
8 practice, there's a fair degree of variability
9 about what goes into those exams and so we were
10 wondering how standardized, how reproducible that
11 particular piece would be.

12 DR. WOODS: So in the chart
13 abstraction tool itself, really the way that they
14 were instructed to abstract it was to first
15 identify the date of the ADHD diagnosis and then
16 evidence of ADHD diagnostic, clinical exam by
17 physician in the chart. So any evidence,
18 evidence in the chart of assessment for symptoms
19 of ADHD including inattention, hyperactivity,
20 impulsivity, to evaluate a diagnostic tool.
21 Evidence in the child consists of core symptoms
22 of ADHD including inattention, hyperactivity,

1 impulsivity, certain things. They were
2 instructed to look broadly on effectiveness on a
3 visit-based assessment.

4 MEMBER KELLER: One other issue that
5 arose was the question that is done in a number
6 of parts of the country where different parts of
7 the ADHD assessment are done not on a single
8 encounter, where people do an assessment --

9 CO-CHAIR SUSMAN: I think we have
10 cross calls here.

11 DR. WOODS: Operator, you need to
12 close your line.

13 In the conversation on the phone, it
14 had slipped my mind that that was the way we
15 instructed the chart abstractors to account for
16 that very thing. So I apologize.

17 CO-CHAIR SUSMAN: That's okay.

18 MEMBER KELLER: That's why we get to
19 ask the question again. Thanks.

20 CO-CHAIR SUSMAN: Ricardo.

21 MEMBER QUINONEZ: So I just have a
22 question about the evidence, graded as B. Being

1 a little bit familiar with the ADHD evidence
2 simply because I'm very interested in over
3 diagnosis, I don't remember and maybe you can
4 educate me as to actual RCTs that linked
5 inaccurate diagnosis of ADHD with bad outcomes.
6 I remember most RCTs are whether treatment works
7 or not. So I mean is there direct evidence to
8 cite such a high level of evidence that complying
9 with this measure would improve outcomes?

10 DR. WOODS: Okay, so I can provide you
11 with more information, but one of the things that
12 I think is particularly concerning, there are
13 kind of two things that are particularly
14 concerning. One is when another type of mental
15 health diagnosis is described as ADHD. They will
16 get potentially stimulant medication that could
17 exacerbate the symptoms of this other condition,
18 if not properly diagnosed. So that's a fairly
19 bad outcome.

20 The other is in the age of stimulant
21 medications. One of the things that happens is
22 kids will show up thinking that they can get more

1 focused or get some drugs and they'll show up and
2 try to get ADHD medications and if you don't do a
3 very systematic diagnostic process, they can
4 pass. So those were -- that's the nature of the
5 literature. I can try to get you specific
6 citations if that would be helpful.

7 CO-CHAIR SUSMAN: So it sounds like
8 more anecdotal than from RCTs?

9 DR. WOODS: No, I'm just saying that
10 off the top of my head I can't list off the 12
11 studies. But let me -- while you're discussing,
12 let me look in the guideline.

13 CO-CHAIR SUSMAN: All right, are there
14 -- yes, Virginia.

15 MEMBER MOYER: To add a little bit to
16 what Ricardo is saying, there's clearly adequate
17 evidence. In fact, high quality evidence for
18 treatment, appropriate treatment. And evidence
19 that if you don't treat, it's not good for the
20 kid.

21 What we don't have, and I know the
22 literature well enough to know that it's actually

1 not there, is evidence that the -- there's not
2 trial which you wouldn't expect, but not even
3 observational evidence about the misdiagnosis.
4 And that, I think, is what we're looking for.
5 We're not looking for randomized trial of
6 accurate diagnosis. We're looking for a study
7 that would tell us how frequently inaccurate
8 diagnoses occur.

9 CO-CHAIR SUSMAN: Okay, well, we'll
10 wait for a response from our developers while
11 we're further discussing.

12 Other points around the evidence here,
13 that this is a measure that's going to -- by
14 having a structured approach to ADHD diagnosis,
15 it's going to lead to improved outcome in the
16 patients? That's a process measure here.

17 I don't see a lot of more questions or
18 input, so I'll give you just another second or
19 two here before we decide to vote.

20 Yes?

21 MEMBER FATTORI: Just a question for
22 the group, particularly those who -- I appreciate

1 the comments that were just made, but doesn't
2 treatment, effective treatment rest on the fact
3 that you have an accurate diagnosis?

4 CO-CHAIR SUSMAN: So there's some
5 shaking of head, yes and no. Let's take pro and
6 con here. Virginia?

7 MEMBER MOYER: Absolutely. I mean
8 that's sort of a first principle. But what we
9 don't have is documentation that inaccurate
10 diagnoses are leading to bad outcomes. We think
11 they would, but we need documentation that that's
12 happening and we also need documentation that
13 using this approach provides you, makes the
14 patient have a better outcome. That's what we
15 don't have. It's not that there's not a
16 theoretical reason --

17 DR. WOODS: So there actually is an
18 interesting new study in Nature and Neuroscience
19 last month that was looking at the ability to
20 focus and doing functional MRI scans for the
21 ability to focus. And they were able to find a
22 particular pattern map, a signature for focus.

1 And then they prospectively got scans of children
2 who had had the standardized tools, both positive
3 and negative, and prospectively predicted very
4 well the ability of the testing. More to come,
5 but that's an interesting little piece.

6 CO-CHAIR SUSMAN: David, do you want
7 to add to the conversation?

8 MEMBER EINZIG: Yes, just a clinical
9 perspective. So people can have, obviously,
10 trouble with concentrating for a lot of reasons,
11 fetal alcohol, autism. There's a lot of other
12 variables. So I'd be less worried about using
13 these forms to diagnose ADHD accurately for the
14 purpose of appropriate treatment with a
15 medication because medications may be appropriate
16 even if you don't have ADHD. But more for the
17 worried, well, the people who are trying to get
18 into their Ivy League colleges and get artificial
19 advantages where this might provide more useful
20 information.

21 CO-CHAIR SUSMAN: Okay, any further
22 comments? I'll take one further comment from our

1 developer, so make it good.

2 DR. WOODS: A question to you?

3 CO-CHAIR SUSMAN: I thought you had
4 something further, your colleague was indicated,
5 but if not, we can move on.

6 DR. WOODS: I had wanted to comment
7 about the issue of finding all of the elements in
8 one visit. That was the last final thing I think
9 I was going to tell you.

10 And as has been already mentioned, it
11 is highly problematic to begin a treatment for
12 ADHD on a child who does not have ADHD. And so
13 therefore, it's very problematic and an important
14 measure. And there's a considerable gap in this
15 at this time.

16 CO-CHAIR SUSMAN: Okay. I'm not
17 seeing or hearing a lot of further discussion on
18 evidence. Yes, David?

19 MEMBER KELLER: So the only other
20 comment was about the performance gap that was
21 identified that that was based on a practice
22 survey of four clinical sites in the greater

1 Chicago area and we were -- the committee
2 wondered whether there might be more. I expect
3 there would be more variation if you did a
4 broader sample, but that's a fairly rarified
5 sample on which to identify a performance gap. I
6 didn't think that was a huge sample.

7 DR. WOODS: So the performance gap is
8 really identified through the literature and what
9 we found was consistent with the performance gap
10 that exists across the country. And this is a
11 national standard, so wherever you find it, you
12 find it. I mean you should find it. But the
13 performance gap is in the literature. Does that
14 make sense?

15 CO-CHAIR SUSMAN: Let's go to vote on
16 the evidence. We've had a nice discussion of
17 what this measure does and doesn't do and I would
18 turn it over.

19 MS. CHAVEZ: Okay, we're now getting
20 ready to vote on evidence for measure 2817,
21 accurate ADHD diagnosis. And for committee
22 members on the phone, the enter options are 1 for

1 high; 2, moderate; 3, low; 4, insufficient.

2 Okay? Ready, go.

3 CO-CHAIR SUSMAN: Remember to click
4 toward our esteemed NQF colleague and click more
5 than once and think good thoughts.

6 MS. CHAVEZ: Twenty-one, 23.

7 CO-CHAIR SUSMAN: Are we trying to get
8 25?

9 MS. CHAVEZ: Twenty-four. I think 25.
10 Okay, so 2 voted high; 16 voted moderate; 5 voted
11 low; and 2 voted insufficient.

12 CO-CHAIR SUSMAN: Okay, and we've had
13 a lot of discussion about gap and documentation
14 or not of that. Any further comments on gap? If
15 not, perhaps we can go on to vote on gap.

16 MS. CHAVEZ: Okay, moving on to voting
17 for gap, same enter options, 1, high; 2,
18 moderate; 3, low; 4, insufficient. Ready, go.
19 Eighteen, 23, 24, 24, 24, 25. Okay, 3 voted
20 high; 21 voted moderate; 1 voted low; and none
21 for insufficient.

22 CO-CHAIR SUSMAN: Okay, reliability.

1 Any questions or further comments about
2 reliability?

3 MR. FINKELSTEIN: I just wonder if the
4 developers want to say anything about the
5 variation in the Kappas across the elements which
6 is pretty striking.

7 DR. WOODS: So on reflection, I've
8 been actually in the measure development business
9 for about 20 years. In 1995, I was part of the
10 initial measure development. When I thought
11 about it, generally things that are not monitored
12 and tracked do not have good standard methods for
13 documentation. There's under documentation.
14 There's documentation in a lot of places. When
15 something is monitored and tracked, people
16 streamline that pretty readily, sometimes over a
17 couple of years or more.

18 When I looked at the results, I
19 thought to myself, well, this abstractor found
20 this, but that abstractor didn't find it. They
21 didn't look maybe as hard. I don't know.
22 Clearly, from what we -- so we went back. We

1 looked at it. And that was kind of what we
2 found. People were looking in different places
3 and not finding things or finding things based on
4 where they were looking because we had them --
5 the abstraction tool asked exactly -- one of the
6 elements was where did you find it?

7 So that's what I would say about it,
8 the natural life course of a measure. And also,
9 probably it's probably appropriate to say for
10 mental health measures, so the mental health
11 documentation in two of the practices that we
12 looked at were not on electronic medical records
13 yet. So there's a diffusion curve that exists.

14 CO-CHAIR SUSMAN: So what are the
15 differences in reliability based on the construct
16 used to define ADHD? So using the Vanderbilt
17 versus clinical assessment, for example?

18 DR. WOODS: We did not see much -- we
19 did not see that one reviewer was finding a lot
20 of direct assessment and the other was not, if
21 that's what you're saying.

22 CO-CHAIR SUSMAN: Well, I'm thinking

1 about, for example, the operationalization of a
2 clinical assessment of ADHD according to DSM
3 criteria might be subject to variation based on
4 the ability to pick up documentation, the
5 interpretation of the elements which would go
6 into assessing things that are in the three
7 domains of ADHD.

8 DR. WOODS: So we only saw two cases
9 of the direct assessment where people found the
10 practice meeting the measure. They found it
11 either with a diagnostic tool that was either
12 validated or not validated.

13 CO-CHAIR SUSMAN: Yes?

14 MEMBER MORROW-GORTON: One of the
15 things that we discussed in the small group was
16 that typically when you make a diagnosis of ADHD,
17 you're not using either clinical history, what
18 you're calling observation --

19 DR. WOODS: No, assessment.

20 MEMBER MORROW-GORTON: -- or
21 checklists. You're generally doing both and
22 using them from multiple places so that you get

1 them more than one location.

2 DR. WOODS: So we're getting the
3 diagnosis, the date of the diagnosis, and we're
4 looking for evidence in the chart of those
5 elements, a validated tool, a physical exam, and
6 the symptoms and impairment in more than one
7 setting. And we're looking for any evidence.

8 It is not necessarily -- I should have
9 clarified that on the call, but all of our
10 instructions and the abstraction tool indicate
11 those things and they're given -- each of the
12 elements that would be included in the validated
13 tool are included as individual items for the
14 direct assessment.

15 CO-CHAIR SUSMAN: Okay, Kevin.

16 MEMBER SLAVIN: One of the questions
17 that came up on the call and that it would be --
18 I think part of the reason why the denominator
19 reliability information would be useful is there
20 were questions about patients who were diagnosed
21 elsewhere who come into a new practice and it's
22 the first diagnosis of those tools and that

1 assessment is not going to be available within
2 that patient's chart, at least where it's being
3 looked for. So I think in terms of the
4 reliability, the denominator information would be
5 kind of useful for those types of issues.

6 DR. WOODS: So we also went back to
7 the -- and met with the chairs of our expert
8 technical panel, Mark Wolraich and Karen Pierce,
9 and presented that question to them. And their
10 assessment -- they work in different kinds of
11 practices, so they had similar opinions, but
12 about different kinds of practices. And their
13 perspective is that generally when a child is
14 moved from one clinician to another, there should
15 be passing forward of this information because
16 the pediatrician is then responsible for the
17 school accommodations, for specific treatment,
18 and one other thing which I can get for you.

19 So they thought that it is standard of
20 care that the new physician should be receiving
21 that information or if they don't get it, they
22 should be looking at doing another assessment.

1 That's their clinical opinion about how this
2 should play out.

3 MEMBER SLAVIN: But I guess the
4 question would be is would that information
5 include the full diagnostic assessment of the
6 child who has been diagnosed or just this is what
7 the child's current needs and the recommendations
8 for the on-going management of the ADHD are?

9 DR. WOODS: Well, their opinion was
10 that the information should be gotten from the
11 sending or the leaving clinician, that there
12 should be -- that appropriate care is really that
13 the pediatrician who is managing the patient
14 should have a criteria-based understanding of
15 what their condition is. And they should get it,
16 however, they can get it, but they most often
17 will get it from the practice that the child is
18 coming from.

19 CO-CHAIR SUSMAN: So I've got David
20 and we'll just go up the aisle here. David E.

21 MEMBER EINZIG: I just wanted to make
22 sure I'm understanding correctly. So we've got a

1 child who is diagnosed with ADHD at the age of
2 five. Moves to Washington, D.C. Is 16 now. Has
3 been stable on meds. So the expectation is that
4 the new provider tries to obtain that document
5 from when they were five? And if they don't get
6 it, they do it again?

7 DR. WOODS: It's unlikely that that
8 would have been their only assessment because --
9 and in fact, another recommendation which we'll
10 talk about in a minute is that there should be
11 regular follow-up and reassessment of children
12 with ADHD, chronic care follow-up.

13 CO-CHAIR SUSMAN: Okay, I'm going to
14 try to wrap this up.

15 David, please?

16 MEMBER KELLER: I keep -- I hate to
17 keep hammering on that point, but I think the
18 reality is that you sometimes can get those
19 records and sometimes can't and as a
20 practitioner, you then have to decide how you're
21 going to handle it. Most of us probably wouldn't
22 do what we would consider a full intake

1 evaluation on that child. We would probably do
2 some sort of grading scales with multiple
3 observations, but not the rest of the assessment
4 that goes into deciding if there are any other
5 diagnoses going on. We would just try to get an
6 assessment of functional status basically to try
7 to make sure that we can keep treating the child
8 because the family is going to be interested in
9 not changing a lot, and that's what they're going
10 to be looking for.

11 I mean it's measuring a different
12 problem because then the problem isn't one of a
13 physician not doing an adequate assessment. It's
14 a physician not being able to get records. And
15 I'm wondering if that was the intent, to kind of
16 conflate those two issues within this measure.

17 DR. WOODS: No. I'll go back to -- as
18 I'm hearing you, you're going to be interested in
19 how this child is actually functioning. You're
20 going to be interested in understanding whether
21 the medication, treatment, or behavior therapy
22 treatment is actually managing the ADHD symptoms

1 and what symptoms are falling out of that.

2 So I mean the idea is there ought to
3 be criteria-based understanding of the diagnosis
4 of the child. And there are a lot of ways to get
5 that. But that's the standard of care and that
6 it should be based on the DSM criteria.

7 CO-CHAIR SUSMAN: Okay. Let's move
8 on. Any new thoughts about reliability? If not,
9 let's vote on reliability. And we have the data
10 concerning Kappa. We have some information
11 that's been described about the potential
12 reliability of the denominators. One, high; 2,
13 moderate; 3, low; and 4, insufficient.

14 MS. CHAVEZ: Voting on reliability for
15 2817. Ready, go. There's 23, 24, 25. Okay, 0
16 voted high; 12 voted moderate; 10 voted low; and
17 3 voted insufficient.

18 CO-CHAIR SUSMAN: Okay, let's move on
19 to validity. Was there any testing of validity
20 in this measure?

21 Martha?

22 MEMBER BERGREN: So there is a 25

1 person expert panel which was described and it
2 was considered case validity and there was not
3 any data associated with that assessment.

4 CO-CHAIR SUSMAN: So by definition,
5 this would be low or moderate?

6 MEMBER BERGREN: Yes.

7 CO-CHAIR SUSMAN: Or insufficient.
8 I'm sorry.

9 DR. WOODS: We did provide data about
10 the face validity in qualitative form and also
11 our public comments on --

12 CO-CHAIR SUSMAN: But this wasn't
13 tested out in the field, correct?

14 DR. WOODS: Correct.

15 CO-CHAIR SUSMAN: Other thoughts from
16 the group at large about validity?

17 David, did you have a thought?
18 Failure to turn. You don't have to keep it up
19 like that. You can just talk.

20 MEMBER MORROW-GORTON: I think one of
21 the conversations that we had during the small
22 group was the sort of diagnostic dilemma around

1 DSM-IV, DSM-IV-TR, DSM-V. And sort of taking a
2 process and sort of moving it to where people are
3 supposed to be moving which is DSM-V. And likely
4 DSM-V will be like DSM-IV and be around for --
5 what is it, 20 years?

6 DR. WOODS: I can respond to that.
7 The changes in the diagnostic criteria for ADHD
8 in DSM-V do not affect the measure. The changes
9 include that you can also assess for autism
10 spectrum as well as ADHD which had not been
11 previously described. And that if there are
12 symptoms of ADHD, initially you had to have
13 symptoms by age 7 and they raised that ceiling to
14 age 12. Those are the only differences which
15 don't affect our criteria.

16 CO-CHAIR SUSMAN: Virginia.

17 MEMBER MOYER: Just one brief comment
18 which is that having been on the call, the
19 committee pre-evaluation comments are quite
20 complete and are a good reflection of what
21 happened at that net conversation.

22 CO-CHAIR SUSMAN: Well, let's go ahead

1 and then consider validity voting here. So
2 remember, this is moderate, low, or insufficient
3 by definition.

4 MS. CHAVEZ: Voting is open.
5 Eighteen, 24, 25. Zero voted high; 9 voted
6 moderate; 11 voted low; 5 voted insufficient for
7 validity.

8 CO-CHAIR SUSMAN: So again, we have
9 this issue of the low and insufficient being the
10 majority. How would you like to proceed, NQF
11 staff? They're doing some gyrations,
12 calculations, but it's going to be 16 versus 9.

13 DR. NISHIMI: Doesn't pass.

14 CO-CHAIR SUSMAN: This is a must pass,
15 so this will stop here.

16 DR. NISHIMI: So just for the record,
17 reliability was in the gray zone, but validity is
18 a not pass.

19 CO-CHAIR SUSMAN: Okay, thank you very
20 much. Any feedback to the measure developers
21 here before we move on to the next one?

22 MEMBER KELLER: So I echo what Jennie

1 said earlier which is that we all think that
2 accurate diagnosis of ADHD is important. I think
3 where we're stuck is exactly what we're measuring
4 and we're concerned. I think some of what you
5 heard and the concern here is that we want people
6 to focus on what's important is going to improve
7 outcomes and not find themselves doing a lot of
8 things just to make the chart look pretty. I
9 think that's underlying a lot of what you heard
10 here, that we want the work that we do to get
11 accurate ADHD diagnosis to matter. And that's
12 what we -- I think that's where we're all
13 struggling in this.

14 MEMBER MOYER: I would also suggest
15 that more empirical testing would probably have
16 made us feel more comfortable. The face validity
17 and the description which was pretty broad didn't
18 leave us feeling as comfortable as we would like
19 to have been.

20 CO-CHAIR SUSMAN: I would say the
21 reliability was a question when you start to look
22 at the individual components.

1 David?

2 MEMBER EINZIG: Just one more quick
3 comment. And also just to emphasize that
4 sometimes ADHD medications are appropriately
5 used, even without an ADHD diagnosis, so I think
6 that's --

7 CO-CHAIR SUSMAN: Okay. We have
8 another ADHD measure which is on chronic care
9 follow-up, 2818. I think we've talked a lot
10 about the issues, so if you could confine your
11 comments to specification and why that
12 specification is valid and important.

13 DR. WOODS: So this is a claims-based
14 measure, also deriving from the 2011 AAP ADHD
15 Guideline that recommends that ADHD be considered
16 a chronic condition and that patients with a
17 diagnosis of ADHD be treated as children and
18 youth with special healthcare needs and that it
19 is very important to treatment appearance to have
20 follow-up visits. This measure is specified to
21 begin a year after ADHD diagnosis. There should
22 be -- the treatment should be managed fairly

1 frequently in the first year where there should
2 be several visits and phone calls to titrate
3 medication or to assess behavior therapy. But
4 following the year after diagnosis, as a chronic
5 condition, in a medical home, the patient should
6 be seen by a clinician at least yearly.

7 In the call, we discussed that there
8 may be many other times where there's a phone
9 call or other kinds of communication more
10 frequently and there could be visits, more
11 frequently, but it's at least one visit every
12 year to manage ADHD. That is currently not
13 happening.

14 In terms of the gaps, data from
15 community-based samples indicate average time to
16 discontinuation of medicine is four months and
17 that families are fully compliant with treatment
18 regimens for an average of only two months.

19 GPA has been shown to be significantly
20 higher during the treatment adhered marking
21 periods than non-adhered marking periods for
22 Medicaid-eligible children diagnosed with ADHD.

1 So it is this chronic care follow-up
2 is guideline-based recommendation which should
3 give it some evidence, strong evidence and it is
4 actually graded B and strong in the guideline
5 itself. And patients with ADHD who receive
6 follow-up visits are more likely to receive
7 treatment which, in turn, improves function,
8 quality of life, and reduces symptoms.

9 There are no unintended consequences
10 from this measure. However, without this
11 measure, negative consequences may occur
12 including poor treatment adherence, ultimately
13 resulting in decreased function and quality of
14 life.

15 CO-CHAIR SUSMAN: Okay. Very good.
16 Thank you.

17 And Virginia, Jill, Kevin, comments,
18 high points in our consideration here?

19 MEMBER MORROW-GORTON: I think we
20 actually were pretty interested in this measure
21 thinking about ADHD as a chronic condition,
22 thinking about follow-up. We did have some

1 conversation about whether or not one visit was
2 adequate, although if you think about it, if you
3 have somebody that is followed by a sub-
4 specialist or who doesn't tolerate medication,
5 there was some question about whether that extra
6 visit would be a burden. I think that's probably
7 not the case. So I think we were pretty positive
8 about this in general.

9 CO-CHAIR SUSMAN: Other comments,
10 Kevin, Virginia?

11 MEMBER MOYER: So one of the concerns
12 that we had is that the evidence is inferential.
13 It's not actually specific to this disorder and
14 so that was a concern. It's basically using the
15 chronic care model and making an assumption that
16 because this is a chronic disease that the
17 chronic care model and the data that have arisen
18 from that would also apply to this disorder. So
19 I think there was -- there is evidence, but the
20 evidence is inferential. It's not direct.

21 DR. WOODS: What I just described to
22 you is actual evidence from studies that

1 demonstrate that follow-up visits lead to better
2 adherence and poorer adherence when there aren't
3 follow-up visits.

4 MEMBER MOYER: Right.

5 DR. WOODS: So that's the evidence for
6 ADHD about the type of follow-up. And I know the
7 discussion about inference was really whether we
8 could believe that ADHD exists, someone brought
9 that up on the phone.

10 CO-CHAIR SUSMAN: Let's not go down
11 that path. I think by a vote how many want ADHD,
12 right?

13 Okay, John.

14 DR. BURSTIN: Folks need to turn their
15 mics off.

16 CO-CHAIR BROOKEY: So just to clarify,
17 if this visit, especially for these older
18 children, is in the context of a well-child visit
19 and they code both a well child and an ADHD, it's
20 going to count, is that correct?

21 DR. WOODS: Correct.

22 CO-CHAIR BROOKEY: Thank you.

1 MEMBER MILLER: I'm sorry, this is
2 Marlene. Did you say that would count or would
3 not count?

4 CO-CHAIR SUSMAN: It would count.

5 MEMBER MILLER: So if a child has five
6 diagnoses, the order doesn't really matter? I
7 was sort of stuck on those last four words of
8 this thing that says "as the primary diagnosis."

9 DR. WOODS: It's specified as primary
10 or secondary diagnosis.

11 CO-CHAIR SUSMAN: So any order, it
12 will count.

13 Kevin?

14 MEMBER MOYER: So the actual
15 specifications are that the follow-up visit also
16 is primary? That isn't what's stated.

17 DR. WOODS: Primary or secondary.

18 MEMBER MOYER: For both. Okay.

19 MEMBER SLAVIN: The studies that you
20 quoted suggest that follow-up leads to improved
21 adherence with medications, but that doesn't
22 necessarily show that there's improved outcomes

1 based on just the follow-up appointment and
2 adherence to the medication.

3 I know there's studies that show that
4 treatment plans do improve certain functional
5 outcomes, but the ones that you're specifically
6 citing, at least if I understand them correctly,
7 just specify that because patients follow up they
8 take their meds, but it doesn't necessarily mean
9 -- it doesn't necessarily get us that final step
10 that the outcome is improved.

11 DR. WOODS: As part of this activity,
12 we did a systematic review which was published in
13 -- what was it, Journal of General Internal
14 Medicine or Annals of General Medicine, something
15 like that. And I can get you the article that
16 actually links. Actually, we were going -- we
17 were supporting an activity of the NCQA who were
18 trying to develop an outcome measure for ADHD
19 because it was possible to demonstrate through
20 the literature that medication and behavior
21 therapy adherence did improve outcomes of the
22 ADHD condition. But if treatment is stopped,

1 there's return to the condition specific symptoms
2 impairment.

3 CO-CHAIR SUSMAN: David.

4 MEMBER EINZIG: So I was just curious
5 as to why just one visit for follow-up for a
6 year? How do you come with one?

7 DR. WOODS: At least one, that's the
8 way it's stated, at least one. It can be more,
9 but it doesn't need to be more for all children.

10 CO-CHAIR SUSMAN: It's a low bar.

11 DR. WOODS: Well, we understand that
12 some of the situations that people were
13 discussing in the other measure, the child may be
14 managed. And you just have to check in and make
15 sure.

16 CO-CHAIR SUSMAN: Carol and then John.

17 MEMBER STANLEY: Yes, can you explain
18 a little bit about does the prescribing provider
19 have to be the one to do the follow-up visit?
20 Because with Medicaid population, there's
21 frequent changes in PCP and in health plans
22 sometimes, especially if foster care. So when

1 operationalizing this measure, was it taking into
2 account, did it have to be the same provider that
3 was prescribing that did follow-up?

4 DR. WOODS: We did not go with the
5 prescribing provider because that was one of the
6 key issues with ADHD measures. Previously,
7 states could not really use the measure because
8 federally qualified health centers don't provide
9 the DEA numbers of the physicians.

10 MR. FINKELSTEIN: So these are very
11 quick questions and neither is disqualifying, but
12 I just am trying to understand. What if a
13 patient is seen in my practice and then moves to
14 Nebraska? So there's no evidence of any visit at
15 all in that following year, but there's also no
16 documentation in the chart that they've left. So
17 I just wonder, if we just have to not worry about
18 that, so that's number one.

19 Number two, can you clarify for me are
20 these calendar years? So if I'm diagnosed in
21 December, December 2015, is it that there's a
22 visit in 2016, which is kind of month 2 through

1 14 and if I'm diagnosed in January of 2015, it's
2 month 14 through 26?

3 DR. WOODS: Yes. It's based on the
4 time between diagnosis and the next visit. So
5 it's a year and a day from your diagnostic.

6 MR. FINKELSTEIN: Not calendar year,
7 it's not calendar year, it's a year and a day.

8 DR. WOODS: Okay, what you described I
9 thought --

10 MR. FINKELSTEIN: It's not calendar
11 year, right.

12 DR. WOODS: Right, because the idea is
13 it is recommended practice to see a child many
14 more times in the first year and that's not the
15 chronic care management part of things. It's the
16 titration of medication. It's the determination
17 of effective treatment, whereas beyond a year,
18 that's where the chronic management takes up.

19 CO-CHAIR SUSMAN: Okay, Ricardo.

20 MEMBER QUINONEZ: So I just wanted to
21 comment on the one-year issue. I actually think
22 the opposite. I don't think it's a low bar. If

1 a clinician who is managing this condition has
2 very good communication with the family,
3 including phone calls, emails, etcetera, that's
4 good care. And so I think a year is not bad.

5 CO-CHAIR SUSMAN: A year seems to me
6 to be arbitrary.

7 MEMBER QUINONEZ: Arbitrary, so I'm
8 saying I don't think it's a low bar. It's
9 actually -- you could argue if you have good
10 communication with the family and the child is
11 actually doing well, then a year may be too much.

12 CO-CHAIR SUSMAN: Today, in most
13 advanced systems, certainly there are other means
14 of communication than a visit to the physician.
15 I think you make a good point there.

16 David.

17 MEMBER KELLER: So one of the things
18 that happens in the management of this chronic
19 disease is that families decide to opt out, that
20 there are families who decide that their children
21 should not be on medication. They don't want
22 their child on medication and for those families,

1 I've always found it challenging to bring them in
2 for anything other than their well visit. And
3 we'll get into my coding issue with the well
4 visits because I think that is an issue later.
5 But for kids who are not actively and they opt
6 out of behavioral health treatment, behavioral
7 therapy as well, and just say they'll manage it
8 by themselves. I had a substantial number of
9 those folks. I don't know how prevalent that is
10 nationally. But I'm wondering if that came up in
11 any of your discussions because with families,
12 the decision to medicate is actually a pretty
13 major one, that families make for a variety of
14 reasons, some of which is evidence based and some
15 of this is just based on what they hear and from
16 a variety of people or their previous experience
17 with medications and their family members and
18 things like that.

19 DR. WOODS: There was some discussion
20 of that issue. Our expert panel believed that it
21 was a part -- like if someone doesn't take their
22 diabetes medicines or they don't take their blood

1 pressure medicines or cholesterol medicines, that
2 it is a part of this chronic care management to
3 bring a patient in and have those difficult
4 conversations. Difficult conversations happen.

5 And what are the concerns? Well,
6 maybe there are some side effects. Maybe there
7 are things that the physician doesn't know about.
8 So we did discuss that and this -- our expert
9 technical panel that included parents felt that
10 this is part of good chronic care.

11 CO-CHAIR SUSMAN: So let's try to wrap
12 this up.

13 Virginia?

14 MEMBER MOYER: Remind me whether this
15 is a provider level or a health plan level
16 measure.

17 DR. WOODS: So we were unable in the
18 testing context, we were working with the Truven
19 MarketScan database and they cannot give us
20 provider-level information, not that they don't
21 have it. It is with their contract, the way they
22 get their data, they're not allowed to share that

1 information with us, but they could share with us
2 whether it was a Medicaid or the types of
3 insurance.

4 CO-CHAIR SUSMAN: So this is a
5 population-based measure?

6 DR. WOODS: Yes.

7 CO-CHAIR SUSMAN: Thank you.

8 MEMBER MOYER: It's intended to be a
9 health plan level measure because that is
10 actually relevant to John's question about
11 somebody moving to Nebraska. They're out of the
12 health plan, so they're no longer in your
13 denominator.

14 CO-CHAIR SUSMAN: If they have
15 continuous enrollment for a specified period.

16 MEMBER MOYER: Right.

17 CO-CHAIR SUSMAN: Okay, are there any
18 other new perspectives? Not seeing any, let us
19 move on to consideration of evidence.

20 MS. CHAVEZ: Okay, voting for evidence
21 for measure 2818, ADHD chronic care follow-up is
22 now open. We are expecting 25 votes. I guess 24

1 votes. I see 22, 23. It would be 23 votes.

2 There are two people out. Twenty-four.

3 CO-CHAIR SUSMAN: Are we set?

4 MS. CHAVEZ: Okay, so 2 voted high; 17
5 voted moderate; 3 voted low; 2 voted
6 insufficient.

7 CO-CHAIR SUSMAN: Okay, gap. Any
8 comments on gap? I think we've at least touched
9 a little bit on this.

10 MEMBER MORROW-GORTON: I think from
11 the conversation we had that their performance on
12 the measure is fairly low, 50 percent. We don't
13 know individual provider. It's probably really
14 variable and there were some disparities in terms
15 of minorities and the documentation of follow-up
16 visits for them compared to the general
17 population.

18 CO-CHAIR SUSMAN: Do we have actual
19 plan level data on gap or is it all amalgamated?

20 MEMBER KELLER: We have Medicaid.

21 CO-CHAIR SUSMAN: Okay, but not one
22 plan versus another plan.

1 MEMBER KELLER: Although there was a
2 disparity between Medicaid and commercially-
3 insured patients.

4 CO-CHAIR SUSMAN: Any other comments
5 about gap? Let's vote.

6 MS. CHAVEZ: Okay, voting on gap.
7 Eighteen, 24, 25. So 5 voted high; 19 voted
8 moderate; zero for low; and 1 insufficient.

9 CO-CHAIR SUSMAN: Moving on to
10 reliability. Was there any empiric reliability
11 testing of this measure? And if so, what were
12 the results?

13 DR. WOODS: What we did was compare a
14 sample with the remainder and found strong
15 reliability.

16 DR. NISHIMI: So in this case, the
17 developer appears to be relying on validity
18 testing at the data element level. So however
19 the committee judges that approach would then
20 carry into the reliability field. So if you vote
21 moderate validity at the data element level, then
22 it would be moderate validity at the -- we don't

1 require separate reliability testing if they've
2 conducted validity testing that you judge as
3 adequate at the data element level.

4 DR. WOODS: And I can read the results
5 if that would be helpful.

6 DR. NISHIMI: I think the committee
7 has it in front of them.

8 MEMBER KELLER: So this is where
9 though I had some concern only because of what
10 I've been told by various coders over the
11 generations which is the well visit, how to code
12 a well visit. And I've been told at different
13 times to code many diagnoses and to code only a V
14 code, depending on what they believe payers are
15 paying at that given time.

16 ***PART 3 Section B*** 1:35:54

17 There was a time where a number of
18 payers would only pay -- basically, if you did a
19 code 25 and merged a prevention code and an
20 illness code at the same time, the payer would
21 pick the one that cost the least and pay that one
22 and deny the other claim.

1 And particularly in Medicaid which at
2 least in two of the states I've worked in pays
3 significantly better for preventive care than it
4 does for acute care, we were encouraged to not
5 code for diagnoses like asthma and ADHD during
6 visits that involved well child care.

7 I don't know how prevalent, again,
8 that practice is, but I'm concerned that a number
9 of visits where ADHD -- it's pretty typical to
10 address ADHD during a well visit when you're
11 seeing a child who has ADHD. So whether you code
12 for it or not, I'm concerned that we would be
13 losing a lot of that information if we relied
14 solely on coding.

15 CO-CHAIR SUSMAN: Kerri.

16 MEMBER FEI: In reviewing here, I'm
17 noticing that the exclusions use the medical and
18 patient reasons for exclusion, those buckets.
19 Are those specified -- are all of those possible
20 reasons specified out and available via coding?
21 Because usually that's a provider level method of
22 exclusion for measures and aren't able to be

1 collected administratively.

2 DR. WOODS: You mean like -- the
3 exclusions are codes for autism, substance abuse,
4 anorexia, mood disorders, and anxiety.

5 MEMBER FEI: So only those and they
6 can't do anything else. Okay. Usually those
7 aren't all coded out. Secondly, since it is a
8 health plan measure, I see continuously enrolled
9 during the measurement year, not continuously
10 enrolled during the measurement year, excluded.
11 There's no allowable gap.

12 CO-CHAIR SUSMAN: So one of the
13 questions I think remains around this issue of
14 can the validity testing stand in for reliability
15 testing here, and I guess I'm not clear that
16 you've done anything more than face validity
17 testing or maybe I'm not getting it, seeing it.

18 DR. WOODS: Reliability testing.

19 CO-CHAIR SUSMAN: Or maybe one of the
20 folks who really took a better look at this could
21 help out.

22 MEMBER KELLER: We had that same

1 concern that the validity testing seemed to be
2 face validity testing.

3 DR. WOODS: "For critical data element
4 testing, each measure component, numerator and
5 denominator exclusions were tested through
6 implementation. Results were reviewed and
7 reliability was assessed based on comparison with
8 the total ADHD population and Medicaid, CHIP, and
9 commercial insurance respectively. Results of
10 the analysis of the measure led to substantial
11 changes in the initial proposed specifications.
12 The components were iteratively tested until
13 results indicated the measure specifications were
14 capturing the correct population. For
15 performance measure score, the measure was
16 implemented in a Truven MarketScan database and
17 performance was compared to performance of the
18 initial core ADHD follow-up measure."

19 "Administrative claims" -- so there's
20 also a different measure that we compared it to.
21 "In the critical data element testing of the
22 Medicaid population, 22.52 percent of the

1 denominator population had a valid specific
2 psychiatric E&M visit with an ADHD diagnosis code
3 in the measurement year. Similarly, 13.43
4 percent of the denominator population had a valid
5 other psychiatric E&M visit with ADHD" -- I can
6 continue. Shall I? I'm trying to give you a
7 sense that you have --

8 CO-CHAIR SUSMAN: I'm not sure.
9 Virginia, do you want to comment?

10 MEMBER MOYER: Yes. I actually read
11 all of that several times and I still don't
12 understand what was done for validity testing to
13 know whether what you say you were measuring is
14 what you are actually measuring. Testing it
15 against the rest of the sample tells you that you
16 got a good random sample.

17 DR. WOODS: Okay, so initially we were
18 asked about reliability testing and that's what I
19 was just reading for you is what we did for
20 reliability testing. I can read you what we did
21 for validity testing.

22 MEMBER MOYER: I've read it. I don't

1 need you to read it to me, I need to understand
2 it better. That's where I'm struggling.

3 DR. WOODS: Help me understand what
4 was problematic.

5 CO-CHAIR SUSMAN: Use your microphone,
6 if you would. Thanks.

7 MEMBER KELLER: So what we don't --
8 what I'm not understanding is what was the gold
9 standard and --

10 DR. WOODS: Complementary analyses.

11 MEMBER KELLER: Say that again?

12 DR. WOODS: Complementary analyses.

13 MEMBER KELLER: What's that?

14 CO-CHAIR SUSMAN: What does that mean?

15 DR. WOODS: We implemented the
16 existing CHIPRA initial core measure of ADHD and
17 compared it to our proposed version.

18 MEMBER KELLER: So you took the
19 initial -- the current standard, the current
20 CHIPRA standard and compared the results against
21 this?

22 DR. WOODS: Yes. We also examined the

1 likelihood that children met the follow-up
2 requirement with an E&M visit versus a non-
3 psychiatric visit.

4 All individuals in the denominator --
5 so we also assessed the denominator eligibility,
6 inclusion, and exclusion.

7 MEMBER KELLER: So essentially, you
8 used the CHIPRA standard to create a gold
9 standard and then you compared and said this
10 works the same as the CHIPRA standard does.

11 DR. WOODS: Better, works better.

12 MEMBER KELLER: In the Truven
13 database. Okay.

14 CO-CHAIR SUSMAN: Was there any then
15 reporting of the statistical analysis between the
16 level of agreement between those two databases?

17 DR. WOODS: "Results of testing of the
18 new specification of the enhanced ADHD follow-up
19 measure to assess chronic care follow-up were
20 strong. High-level results include that 63
21 percent of Medicaid enrollees and 49 percent of
22 commercial enrollees who had sufficient coverage

1 and were diagnosed with ADHD in 2010 had any
2 valid E&M visit for ADHD diagnosis code in the
3 measurement year."

4 CO-CHAIR SUSMAN: Okay.

5 MEMBER MOYER: That was results, but
6 did you have comparative results?

7 DR. WOODS: I'm looking for them. It
8 appears we may not have reported on that, but we
9 have it, so I can get it for you. Just to tell
10 you what we were thinking, we were concerned --
11 we wanted to be sure that we were not losing a
12 lot of children, but our look-back periods and
13 you know that year, and we would consider it non-
14 valid to have a lot of children falling out and
15 so we found that they were not falling out and we
16 should have reported.

17 CO-CHAIR SUSMAN: I guess I'm still
18 personally unclear what you did with regard to
19 validity testing beyond face validity and
20 reliability testing and the description that it
21 was done doesn't feel sufficiently detailed for
22 this process. But let me go on and get Carol.

1 MEMBER STANLEY: I think maybe it
2 would be helpful to hear how you know that
3 conducting this measure using administrative data
4 will give you the same results as using medical
5 record abstraction.

6 DR. WOODS: We did not -- and
7 generally, it's not done to do reliability
8 testing of administrative claims versus chart
9 review. And our goal was -- our goal was to have
10 this measure used by Medicaid which was part of
11 the program that we were involved with. And
12 Medicaid, generally, won't use chart review
13 measures. So we did the best that we could with
14 an electronic administrative claims measure.
15 Administrative claims measures have their
16 challenges. And this will equally have those
17 challenges, but they won't be used.

18 CO-CHAIR SUSMAN: Okay, clearly,
19 there's limitations in any data, some stronger
20 than others. We might go on to Jon.

21 MR. FINKELSTEIN: So if there's an
22 opportunity to come back to this measure, I would

1 ask you to go back and really look carefully at
2 the specifications for the numerator and the
3 denominator because I don't think they make clear
4 what you were saying before. There's language
5 about calendar year. There's language about a
6 measurement year and a prior year. These are
7 these 12-month periods you're talking about and
8 it needs to be much more clearly specified so
9 there's no confusion.

10 DR. WOODS: Right. So it ends up
11 being a bit of a lag, right? So they have to be
12 continuously enrolled and then it has to be a
13 year.

14 MR. FINKELSTEIN: So I understand --

15 DR. WOODS: -- from the diagnosis.

16 MR. FINKELSTEIN: I understand what
17 you're aiming for. I'm saying it's not clear as
18 written. I've now read it several times.

19 CO-CHAIR SUSMAN: So unless there's
20 anything new, why don't we go ahead and vote on
21 reliability and then validity. I think there's
22 been a lot of useful comments. One through four

1 on reliability.

2 MS. CHAVEZ: Okay, voting for correct
3 is now open. Eleven, 21, 23, 25. Zero voted
4 high; 5 voted moderate; 13 voted low; 7 voted
5 insufficient. And this does not pass
6 reliability.

7 CO-CHAIR SUSMAN: So this doesn't
8 pass. I guess we do not need to go on, but I
9 guess my feedback would be to really try to work
10 with the NQF around the validity/reliability
11 testing and making it clear. You may well have
12 done everything that's necessary, but it was
13 difficult to tease that out and albeit we're not
14 as facile with the data as you are. Any other
15 feedback?

16 CO-CHAIR BROOKEY: I just have one
17 comment about moving towards more virtual
18 medicine, especially in this field. It may be
19 appropriate to have video visits. It may be
20 appropriate to have telephone visits, especially
21 for the stable children. And developers I think
22 should consider the fact that those are really

1 legitimate ways to provide care. And I think
2 they should be included in some of these
3 measures.

4 CO-CHAIR SUSMAN: That goes along with
5 what Ricardo was saying earlier.

6 Okay, you've had enough of me, so
7 we're going to make a switch and John has the
8 unenviable task of going through a host of
9 related measures. And hopefully, he'll find some
10 magical way to get us back on time.

11 DR. WOODS: I had one question about
12 the accurate diagnosis measure. Is there any
13 follow-up that I can do or we can do regarding
14 that?

15 DR. NISHIMI: We'll follow up with you
16 after the meeting.

17 DR. WOODS: Okay.

18 CO-CHAIR SUSMAN: Thank you very much.
19 Should we take a five-minute stretch before we go
20 in --

21 CO-CHAIR BROOKEY: Why don't we take a
22 five-minute stretch and then we'll go into the

1 ten measures.

2 DR. NISHIMI: Literally five. This
3 will be a little bit of a slog.

4 (Whereupon, the above-entitled matter
5 went off the record at 1:49 p.m. and resumed at
6 1:55 p.m.)

7 CO-CHAIR BROOKEY: It turns out to be
8 ten measures. We're on 2770 family experience as
9 for coordination of care, FECC measure set. And
10 I understood that from the discussion with the
11 member group that it was decided that we would
12 vote on all of these ten individually. Is that
13 correct? Okay.

14 And so the good news is that for some
15 of these, the evidence is based on the same
16 studies. And so we may be able to sort of lump
17 some of these together although we will still
18 vote on them individually. So we're going to
19 have to be -- we're going to ask both the
20 developers and the members who are on point for
21 this, I think it's Tim and Marlene, to try to
22 clarify if a particular measure, if the

1 discussion doesn't need to be as long because we
2 just talked about something where the evidence
3 may have been the same for this particular
4 question on the survey.

5 So having said that, let's turn to the
6 developers to give us an overview of these
7 measures.

8 DR. LION: My name is Casey Lion. I'm
9 with Seattle Children's Research Institute and I
10 am going to be introducing to the family
11 experiences with coordination of care, FECC
12 measure set which is 2770 from the Center of
13 Excellence on Quality of Care for Children with
14 Complex Needs. And there are measure development
15 processes similar to what you heard about this
16 morning for the mental health measures. I will
17 review it very briefly now.

18 So our Care Coordination Working Group
19 began by developing a conceptual framework. We
20 then used the conceptual framework to guide six
21 separate literature reviews in domains that
22 seemed to be related to care coordination related

1 processes that might have impacts on short and
2 long term health outcomes. We then used the
3 evidence from these reviews to develop each of
4 the proposed measures. Then presented the
5 measures to a multi-stakeholder Delphi panel
6 which included caregivers of children with
7 medical complexity.

8 Measures that met these validity
9 criteria were then operationalized and underwent
10 cognitive interviews with families in both
11 English and Spanish.

12 We then field tested the measures in a
13 sample of over 1200 caregivers of children with
14 medical complexities in two state Medicaid
15 programs. Of the 21 original FECC measures that
16 we field tested, we've submitted for endorsement
17 the 10 measures with the strongest evidence from
18 the literature, demonstrated performance caps,
19 and the most compelling testing results for
20 reliability and validity.

21 The FECC measures that we have
22 submitted includes ten separate measures which

1 can be used either independently or in any
2 combination to assess to quality of care
3 coordination processes provided to children ages
4 0 to 17 with medical complexity. These are all
5 survey based caregiver reported measures as
6 caregivers are presently the most reliable source
7 for this information which addressed the family
8 perspective and are not reliably documented in
9 the medical record.

10 Examples include whether the child's
11 care coordinator assisted with completing
12 specialty refers, whether the child has a shared
13 care plan. Measures do use billing data to
14 identify the overall denominator population of
15 children with medical complexity using the
16 pediatric medical complexity algorithm or PMCA.
17 The PMCA has also been separately tested and
18 demonstrated excellent sensitivity and
19 specificity for identifying children with medical
20 complexity in both Medicaid claims and hospital
21 discharge data.

22 The ten measures are all supported by

1 some empiric evidence with the exception of
2 FECC-14 which is supported by strong expert
3 consensus. Additional evidence for FECC-14 and
4 17 were recently circulated to the committee
5 following the work group call. The majority of
6 measures demonstrated good reliability although
7 two were limited by small sample size and all of
8 the measures demonstrated excellent face validity
9 and convergent validity with at least one other
10 care experience outcome measure.

11 CO-CHAIR BROOKEY: That was a great
12 summary. Thank you. Very concise. Before we
13 move on, are there any recusals from voting?
14 Okay.

15 Okay, I understand that for the
16 evidence discussion that the first few measures,
17 1, 3, 5, 7, 8, or 9 rely heavily on one RCT and
18 so I wonder if maybe we should just begin our
19 discussion about those measures first and we can
20 vote on those because I think it might be more
21 helpful to kind of break these apart just a
22 little bit.

1 I don't know if that makes sense, Tim
2 or Marlene, but just a suggestion. And is it
3 going to be you or Marlene that leads off the
4 discussion?

5 MEMBER MILLER: We really haven't
6 talked about it, so I'm fine or Jim can do it,
7 too.

8 Do you want me to open with my
9 comments then?

10 CO-CHAIR BROOKEY: Tim has volunteered
11 to go first, okay?

12 MEMBER MILLER: Okay.

13 DR. NISHIMI: You need to use the mic.

14 MEMBER BOST: For FECC-1, there was
15 one randomized control study, one cohort study,
16 and five case series, case control or
17 historically controlled studies that demonstrated
18 that outcomes improve when caregivers of children
19 with medical complex report that their child has
20 a designated care coordinator. For FECC-1,
21 besides what you already pointed out, about one
22 RCT, there was also the committee was concerned

1 about a lack of clarity about who the care
2 coordinator is. Many insurers assign care
3 coordinators for high utilization patients. That
4 coordinator would have different responsibilities
5 than a clinically assigned care coordinator.

6 MEMBER MILLER: Yes, this is Marlene.
7 I guess I would add in the one RCT was really
8 limited is how I best say it because it only
9 involved 100 children and it only followed them
10 for 6 months which seems insufficient to really
11 comment on improvements in chronic conditions
12 when you're following them for 6 months.

13 I think more importantly other than
14 the fact that there is that one very, very short
15 RCT in there was that the RCT was not about
16 involving a care coordinator. It was the small
17 type factorial intervention of which it's
18 impossible to say that the breakdowns that have
19 happened into these six or seven questions that
20 stem from them are the logical pieces at all.
21 Particularly, you know, having a care coordinator
22 as Jim just said that may have other names in

1 other settings of care, so trying to extrapolate
2 from this very, very short study involving 100
3 children for 6 months and then using that one
4 name of a care coordinator, I didn't see the
5 evidence that was there to warrant the measure.

6 CO-CHAIR BROOKEY: Does the developer
7 want to respond to that concern?

8 DR. LION: Sure. So to begin with in
9 the survey, the way we operationalized the survey,
10 we actually set up the questions to try to figure
11 out exactly who might be coordinating care for
12 these children. So we allowed for the fact that
13 it might be somebody, it might be the main
14 provider. It might be someone within the
15 provider's office. It might also be someone
16 outside of the provider's office, for instance, a
17 care coordinator assigned by an insurance plan
18 for high utilizers, for example.

19 So the questions were actually framed
20 as did anyone in the main provider's office help
21 you to manage your child's care or treatment from
22 different doctors or care providers? And then

1 did anyone else outside of the main provider's
2 office help you to manage your child's care or
3 treatment from other doctors or care providers?

4 And we developed that language through
5 our cognitive interview process with families
6 because care coordinator was not actually
7 universally understood by families as meaning
8 precisely what we thought it would mean.

9 And then with regard to the concern
10 about the studies that we used as evidence,
11 mostly relying on multi-factorial interventions,
12 that is essentially true across the board of just
13 about all of the evidence that we have. And at
14 the end of the day, those are the studies that
15 had been conducted. They've all been sort of
16 bundled interventions.

17 We also know from other research that
18 bundled interventions are more likely to be
19 successful than single component interventions.
20 So it may not be possible to actually or even
21 advisable to try to extricate individual
22 components of these bundled interventions. It's

1 something that we recognize and we own, but we
2 did the best that we could with the evidence
3 that's available.

4 CO-CHAIR BROOKEY: Okay, are there
5 questions or comments from the members? Go
6 ahead.

7 MEMBER KELLER: So yes, I would echo
8 what you just said and just wanted to point out
9 that I think one of the strengths of this measure
10 is that unlike the studies where someone was
11 designated by an external force to be the care
12 coordinator, what this measure is looking at is
13 the parent's perception of whether or not there
14 is a care coordinator. And I would submit that
15 that's actually much more important than where
16 the care coordinator is located. If the parent
17 perceives that they have one, I would bet that
18 that's an important measure. So I like that. It
19 really builds on the evidence that's out there.

20 CO-CHAIR BROOKEY: Other comments? Go
21 ahead, Amy.

22 MEMBER HOUTROW: So I really

1 appreciate how in the survey that you guys were
2 able to distinguish what type of person was
3 providing the care, but the use of one RTC that
4 uses an inside force for six months, I think when
5 we talk about the evidence that's where we're
6 talking about being concerned.

7 And the expectation of an in-practice
8 case manager in all of these different studies is
9 really kind of different than if families were
10 identifying that their care coordinator was
11 somebody from their insurance company, for
12 example. And maybe that's not such a big deal
13 with whether they have it or not, but the
14 activities that fall below. So maybe my comment
15 goes better with the rest of the different items
16 that we're going to be talking about that
17 follows. But I think you were very wise to work
18 on perception and identification in the survey.

19 CO-CHAIR BROOKEY: Other questions?
20 So just to clarify, if I could ask, are you
21 saying that the evidence is stronger for the
22 entire set of measures as opposed to any

1 individual component of the set?

2 DR. MANGIONE-SMITH: I would say that
3 that's a fair interpretation. When we saw how --
4 the intervention in any evidence we found were
5 bundled, it was by choice that we felt measures
6 should look at those individual components
7 because there was no way to tell which of them
8 drove the better outcomes that were arrived at in
9 those studies. So that's exactly right. We
10 really feel the evidence for several of these
11 measures come from those bundled interventions.

12 CO-CHAIR BROOKEY: I know there's a
13 question down there, but I just wanted to bring
14 up that the question for the group then, the
15 decision previous to this meeting, was to go
16 ahead and vote on these as individual components
17 as opposed to a bundle. So I want to be clear if
18 that's still the direction here. Are there any
19 comments about that before we move on?

20 CO-CHAIR SUSMAN: I mean it seems to
21 me from what you're saying and reading through
22 this this really makes more sense as a whole, as

1 a bundle rather than breaking it down into all
2 these little component parts. I didn't study it
3 as long as some of you did, but that's just my
4 general sense.

5 MEMBER MILLER: This is Marlene. I
6 guess I would say that I would take it even to a
7 different level. Instead of ten questions that
8 parse out tiny aspects of the bundle, was there
9 -- is there a possibility we could instead have
10 two or three questions that get at more of a
11 larger construct that don't confine us to, for
12 example, exact wording, did your care coordinator
13 ask about a concern. I know it's very hard to
14 think at that minutiae level when we know that
15 the whole intervention was much more than that.
16 So when you say bundled or individual, I guess
17 I'm saying is that I think -- I kept wondering
18 myself is could we have not done ten questions
19 and maybe done two or three at a bit higher
20 level and really gotten something a little easier
21 to wrap our heads around.

22 CO-CHAIR BROOKEY: Go head.

1 MEMBER DORSEY: My question for the
2 developers is related, which is just trying to
3 grapple with what's the rationale, given the
4 conversation that we've had to break these out
5 into their component parts. And since it doesn't
6 seem to be directly supported by the evidence
7 that you all produce in the application, is this
8 more an issue of how you intended to be used and
9 that you're trying to make discrete information
10 about specific components so that individual
11 providers can evaluate where their care
12 coordination may be breaking down? I mean it's
13 not explicitly stated, but I'm trying to figure
14 out sort of what's the balance or rationale here.

15 DR. MANGIONE-SMITH: That's exactly
16 why we didn't want to go from our global
17 constructs. Our hope is that people could track
18 these measures over time and understand where are
19 they falling down in terms of their care
20 coordination services, so what are families
21 telling them they're not meeting in terms of
22 helping us get community services, helping us get

1 sub-specialty appointments when we need them.

2 Several of the more detailed things that have

3 been broken out here.

4 It's also partly why we wanted these

5 to stand as individual measures is these are not

6 measuring a single domain. There are several

7 different aspects of care coordination being

8 captured by the different measures and depending

9 on what it is you're trying to accomplish with

10 your care coordination project or program, not

11 all of these are going to apply. And that's why

12 we wanted to suggest to people you don't have to

13 ask all of them to understand whether you're

14 giving high quality care coordination or not.

15 You can ask specific measures that make sense for

16 the program that you're trying to implement and

17 improve on care coordination with. So in that

18 way, it's very different than say, for instance,

19 the CAHPS measures where you really are supposed

20 to ask the whole survey, right, in order to get

21 at whether experience is good. That's a much

22 more global sort of thing, but this was really

1 trying to help people understand where they're
2 doing well in care coordination from the family
3 perspective and where they're not doing so well
4 and they may want to put some of their
5 improvement efforts.

6 CO-CHAIR BROOKEY: So what I would say
7 is that we put on the table the question of
8 bundling two to ten measures and vote on them
9 individually with the understanding that in the
10 future these could be brought back together as a
11 bundle. So I think that that would be cleaner
12 today if there is no disagreement. We'll go
13 ahead and talk about each measure with the
14 understanding that if some of them do not pass,
15 it doesn't mean that in the future they could be
16 reconsidered or even brought back together as a
17 bundle. I'm not quite sure any other way to do
18 it, especially since the subgroup had decided
19 that it would be better to vote on them
20 individually. Any objections to that?

21 MEMBER MILLER: This is Marlene, but I
22 guess I'd bring up the question, you know, it's

1 one thing to use it to improve your practice, but
2 again when you get to someone being accountable
3 and if we are approving them as individuals, that
4 leaves the door open for some entity to pick or
5 choose one or two of these things where we know
6 the evidence doesn't make sense at this granular
7 level of these ten questions, and then put
8 resources and drive things, holding people
9 accountable to things where there's not direct
10 evidence at that minutiae level.

11 DR. MANGIONE-SMITH: So the level of
12 analysis for these measures is considered the
13 health plan or health system level. They can be
14 used for quality improvement intervention
15 evaluation, but the intent is for them to be used
16 as accountability measures for the complex,
17 medically-complex child population to look at
18 quality of care coordination. So I want to be
19 clear about that. The intention here was to have
20 these be measures of accountability and that the
21 health plan and/or health system would be
22 responsible for improvement on these measures.

1 There were on our Delphi panel,
2 Medicaid health plan representatives. There were
3 parent representatives. There were providers who
4 care for these children who are content experts.
5 These were individual aspects of care
6 coordination that they endorsed as having very
7 high face validity in terms of indicating you did
8 better on these, you were getting higher quality
9 care.

10 CO-CHAIR SUSMAN: So I was trying to
11 look through each of them and see which wouldn't
12 necessarily be applicable for a child with
13 complex disease. I mean could we say that care
14 coordinator helped to obtain community services
15 wouldn't be really germane or appropriate written
16 visit summary content wouldn't be germane. It
17 seemed to me the elements would be applicable to
18 almost every child with complex healthcare needs
19 and therefore why wouldn't we want to measure all
20 those in a single bundle. So I guess I'm going
21 back to that set of concerns that by parsing
22 these out, I mean let's say has care coordinator

1 is the one that some health plan takes for its
2 accountability measure. That could mean anything
3 or not much at all.

4 CO-CHAIR BROOKEY: The real question I
5 have is whether these are actually tested as a
6 bundle versus individual measures.

7 DR. MANGIONE-SMITH: So the survey is
8 actually not a very long survey. It takes about
9 20 minutes to complete and you actually can get
10 20 measures out of it. As we were saying we've
11 only put ten forward for endorsement for the
12 reasons that Casey stated up front. So my
13 assumption and I can tell you from the people who
14 have already asked us for the survey, and are
15 using it for different purposes, currently are
16 all doing the complete survey. They have not
17 been picking and choosing different measures to
18 do. And it was field tested as a whole.

19 CO-CHAIR BROOKEY: Amy.

20 MEMBER HOUTROW: So I think it might
21 help us, maybe to look at the concept map that
22 was provided in this packet because it helps you

1 look at which of these different measures are
2 intended to address different aspects of care.
3 And I also think that when you think about the
4 answers to the questions that parents provided as
5 a survey, let's say they said that their care
6 coordinator was knowledgeable, supportive, and
7 advocated for their child's health. My guess is
8 that they also said yes, that their care
9 coordinator asked about concerns in health
10 changes. And I bet that those two are highly
11 correlated. But perhaps there are other measures
12 here that are left correlated to the other one.
13 So for example, saying yes to question 8,
14 knowledgeable, supportive, and advocated for
15 child's needs, might be highly correlated with
16 concerns in health changes, but not so highly
17 correlated with getting an appropriate after
18 visit summary because those are content and
19 conceptually different. They're not as close to
20 each other on the map.

21 And so for me, the map helps us think
22 about how these things are interrelated to each

1 other and I think that you're making a good
2 point, that these things are important for kids
3 who have complex needs. I don't think anyone is
4 really doubting that those are important, but I
5 think for me, the way I am looking at it is it is
6 about how conceptually close are these different
7 measures and could we potentially lump some of
8 them together as very similar? I think the
9 reason that they're kept apart is because there
10 are unique aspects to the measure that the
11 developers and the Delphi panel thought were
12 important.

13 There were other measures that didn't
14 make it to the table for us, right? So that's
15 why we see not number four, for example.

16 CO-CHAIR BROOKEY: So I'm going to go
17 Tim and then I'm going to start going around the
18 room this way, so Tim, go ahead.

19 MEMBER BOST: So the reason, one of
20 the reasons we've split them was that you will
21 see later on some items basically fail criteria.
22 FECC-15 has no validity assessment. So if based

1 on that, no validity for one of the questions you
2 would have to give validity low. You're going to
3 throw them all out because of one. So it was
4 later on in the process that we decided we needed
5 to split these if you wanted to fairly assess
6 each item because of differences associated with
7 those.

8 But I would also say listening to the
9 two folks, if this is a health plan level, and a
10 health plan can pick and choose the subset they
11 want, you can't get accurate benchmarking because
12 you're basically picking and choosing the ones
13 that you're best at and especially if it then
14 also is used somewhere down the line to evaluate
15 health plan performance. So, you know, I get
16 both sides of this coin.

17 MEMBER FEI: And actually Jim just
18 mentioned what I was going to bring up from the
19 health plan side and to add on to that, he's
20 absolutely right in that respect. If it were to
21 be something that was eventually publicly
22 reported for health plans and consumers were able

1 to make choices, but you're allowed to pick and
2 choose the measures, there's no benchmark --
3 there's actually then no real benchmark or you're
4 being compared to a benchmark that contains
5 everything, when you plan only to choose maybe
6 the things you scored really well on. So if it's
7 going to be endorsed for accountability and
8 someday gets out there for consumer choice or
9 provider incentive or something else, it needs to
10 be this is how you use it as a packaged deal and
11 everyone uses it the same way.

12 MEMBER MILLER: This is Marlene. I
13 would go along with that. If there are some
14 questions, if someone said FECC-15 where there's
15 no validity and maybe that should not be on this
16 panel of questions, comparable to FECC-14 which
17 is really an extrapolation of a very tangential
18 extrapolation from the evidence and maybe those
19 should be removed and we should get to a smaller
20 set of two or three or maybe four questions that
21 we all agree should be asked and always asked as
22 a bundle.

1 DR. MANGIONE-SMITH: So just to
2 clarify, there is validity data for FECC-15.
3 There is not reliability data.

4 CO-CHAIR BROOKEY: Ricardo.

5 MEMBER QUINONEZ: A lot of the things
6 I was going to say had been said, but just to
7 again iterate part of why I think in the phone
8 calls we thought it was important to separate
9 these is there's probably a good reason why NQF
10 puts evidence bases as the number one thing you
11 have to pass first to go on to consider measures.
12 And although a lot of these indicators rely on
13 the same evidence, there are some where the
14 evidence is a lot weaker and so I think that's
15 one of the reasons to vote for these individually
16 because the evidence bases for some of these is
17 very different and much stronger for some and not
18 as much for others.

19 CO-CHAIR BROOKEY: So can I ask you to
20 turn your name tags this way so we can read them?
21 I still can't read your name though. What is
22 your first name again?

1 MEMBER MORROW-GORTON: Jill.

2 CO-CHAIR BROOKEY: Okay, we can't read
3 them because of your microphone.

4 MEMBER MORROW-GORTON: Oh, because
5 it's upside down.

6 CO-CHAIR BROOKEY: There you go.
7 Thank you, Jill.

8 MEMBER MORROW-GORTON: There you go.
9 I'd like to come back to what Amy was talking
10 about in terms of potential correlations between
11 questions. You've got ten questions. Are there
12 questions that track every time? You know if you
13 get an excellent on one, you get an excellent on
14 three, five, and nine, and it's not very helpful
15 to ask all of those questions because it doesn't
16 differentiate. Or is there one or two or some
17 subset that are reflective of people that follow
18 the process so that you didn't need to have all
19 ten of them?

20 DR. MANGIONE-SMITH: Yes, so our great
21 hope going into this was that we would do a
22 factor analysis and we would find like, you know,

1 a beautiful set of five things we could just say
2 this is it. They all measure something different
3 and it's going to get us exactly what we need.
4 We didn't find that. So we just -- we tried and
5 I think to Amy's point, these are really getting
6 at some very separate constructs around care
7 coordination and even though it seems like some
8 of them should really run together, we just
9 didn't find that. They were not correlated with
10 each other and we were hopeful that they would
11 be.

12 CO-CHAIR BROOKEY: Jon.

13 MR. FINKELSTEIN: I agree with keeping
14 them separate because we're in a very difficult
15 zone with evidence, right? There's a huge
16 consensus in the field that kids with chronic
17 conditions, especially complex ones should have a
18 medical home. Care coordination should be part
19 of that. If you try to parse it too finely on
20 which aspects of most evidence, you'll never get
21 there and we'll never have any quality measures
22 on anything to do with this. So I'm really

1 worried about that.

2 I think if we leave them separate, we
3 may come again, through this pathway of
4 insufficient evidence on that micro thing, but
5 meeting all of the criteria for the exception and
6 then seeing some of these ten measures come to
7 the top as kind of more overarching important
8 things that could -- that plans could be held
9 accountable for now with other measures not being
10 endorsed for accountability in that way, but
11 being part of an instrument that could help
12 health systems improve. And I think that would
13 be a fine outcome of this process.

14 CO-CHAIR BROOKEY: So going back to my
15 earlier recommendation, voting separately for all
16 ten measures, which does not preclude in the
17 future requiring the survey to be whole for the
18 health plans to have consistent measures across
19 all health plans. So not to confuse everyone.
20 That means that we'll vote up and down for all
21 ten but there may be further discussion about
22 bundles and I think that might be the best way to

1 get through this. Any disagreement with that?

2 Okay.

3 So any other discussion about the
4 evidence for -- and I guess one question that we
5 have to entertain when we look at the first
6 measure is whether we consider the review to be
7 sufficient to be able to rate it a high or not.
8 So you have to consider that when we vote.
9 Otherwise, if you don't consider the review to be
10 sufficient, it may limit our choices of voting.

11 Are there any other questions or
12 comments about this particular measure and the
13 evidence to support it?

14 DR. NISHIMI: Just to be clear, the
15 developer conducted its own review, but they did
16 report on the quality, consistency and quantity
17 of the evidence. So that's why you can march
18 down that path. If you don't consider that
19 sufficient, then it's not eligible for a high.

20 CO-CHAIR BROOKEY: Questions,
21 comments, confusion? Go ahead.

22 MEMBER FATTORI: Are there any

1 measures that are connected? For example, if we
2 don't move past with the care coordinator
3 question, can we move forward with the other ones
4 that have to do with the care coordinator?

5 CO-CHAIR BROOKEY: Yes. And we're
6 going to do them independently, even though many
7 of them are sort of linked. For this purpose,
8 we're going to go through them one at a time.

9 MEMBER MILLER: This is Marlene. I
10 was confused about the statement you were just
11 making about -- are you trying to suggest we
12 should be ranking based on the thoroughness of
13 literature review or based on what the evidence
14 is showing? I was confused about your comments
15 about --

16 DR. NISHIMI: It's what it's eligible
17 for. It's eligible for high, moderate, low,
18 insufficient. I'm not making a comment on what
19 it should be. It's what you then consider it to
20 be eligible for, the quality of it.

21 MEMBER MILLER: But our lens is still
22 on what does the evidence say about the measure

1 being asked?

2 DR. NISHIMI: Yes.

3 CO-CHAIR BROOKEY: Correct. Jeff.

4 CO-CHAIR SUSMAN: So I have a
5 question, maybe best to the developers. We have
6 these multiple measures. Did we do a separate
7 literature review about each specific element
8 down to the level of, for example, care
9 coordinators, this was specialist service
10 referrals and all the -- or was there just this
11 one larger -- not larger, but one RCT?

12 DR. LION: So we conducted six
13 separate literature reviews that were informed by
14 domains that were identified based on the
15 conceptual model that we've included in the
16 packet, so the domains, the literature reviews
17 were organized around things such as shared care
18 plans, goal setting, information exchange, care
19 coordination.

20 And in all of those separate
21 literature reviews, most of which were conducted
22 by separate people, we were looking for evidence-

1 based links between process measures that were
2 related to that particular item and short and
3 long term outcomes. In most cases we allowed, we
4 preferred pediatric studies, but because of the
5 dearth of pediatric studies, we also included
6 some adult studies, particularly adults with
7 chronic disease.

8 And so on the basis of the literature
9 reviews, we developed the draft indicators that
10 went before the Delphi panel. Did that answer
11 your question?

12 DR. NISHIMI: And just to let you
13 know, the developer did provide the information
14 measure by measure, and so then they just
15 aggregated their reviews and supply the evidence
16 for each individual measure. So they did do
17 that.

18 DR. LION: Yes, so started with --
19 sorry.

20 CO-CHAIR BROOKEY: Marlene.

21 MEMBER MILLER: I was just going to
22 say but even if you did it though with six

1 different reviews, with the vast majority of
2 these, the evidence still comes back to same one
3 RTC.

4 CO-CHAIR BROOKEY: That's correct.

5 MEMBER MILLER: So you're saying that
6 you did six different literature reviews, but
7 they all kept pointing back to one RCT?

8 DR. LION: That is generally true. So
9 for the first set of measures, the one through
10 eight, those all came from the same literature
11 review. Those all related to care coordination
12 within the medical home and care coordinator
13 functions specifically. And so those did come
14 from the same literature review which we then
15 disaggregated in order to present the evidence
16 measure by measure.

17 CO-CHAIR BROOKEY: So is it fair to
18 say that for those measures, we probably will be
19 looking at the same outcome in terms of whether
20 we support them or not? Okay.

21 So Amy, you have a question?

22 MEMBER HOUTROW: I have a procedural

1 question about the issue between high and
2 moderate for number one which is how is the --
3 care coordinator. When we're looking at the
4 evidence, the evidence is about a bundled set of
5 activities that a care coordinator does. But if
6 you have hired a care coordinator, they exist.
7 You must then assume they are doing things. I
8 mean I'm having a little trouble with the high to
9 moderate based on just the presence versus the
10 activities that exist that they do.

11 DR. NISHIMI: That's a decision you
12 need to make. Yes.

13 CO-CHAIR BROOKEY: If you have issues
14 with that, then you can't rank it higher than
15 moderate, so that's an individual decision you'll
16 have to make. Are there other questions or
17 comments before we -- are you ready for a vote?
18 Okay. Let's move forward.

19 MS. CHAVEZ: Okay, we're ready to vote
20 on measure 2770-1, family experiences with
21 coordination of care, FECC-1. We are expecting
22 24 votes on this. Ready, go. For the folks on

1 the phone, it's 1, high; 2, moderate; 3, low; 4,
2 insufficient. Nineteen, 21, 22, 24. Thank you.

3 Okay, so 5 voted high, 15 voted
4 moderate, 2 voted low, and 2 insufficient.

5 CO-CHAIR BROOKEY: Great. That's a
6 great first start. And we have nine more to go.
7 We're going to go through evidence on each one.
8 So we're going to go to the next one which is
9 FECC-3, I believe, and I think either Jim or
10 Kerri are going to lead on this discussion.

11 MEMBER BOST: Basically, the evidence
12 is identical.

13 CO-CHAIR BROOKEY: Any comments about
14 this measure?

15 MEMBER MILLER: Could you use the
16 microphone?

17 MEMBER FEI: I thought I was. I'm
18 sorry. It builds on the first question.

19 CO-CHAIR BROOKEY: So are we
20 comfortable voting on it based on the evidence
21 being the same as for the first? Okay. So let's
22 move forward.

1 MS. CHAVEZ: Okay, voting on FECC-3
2 evidence. Eighteen, 22, 23. Okay, 2 voted high;
3 17 for moderate; 3 for low; 1 insufficient.

4 CO-CHAIR BROOKEY: The next evidence
5 is FECC-5, care coordinator asked about concerns
6 and health changes and again, Kerri and Karen are
7 the leads.

8 MEMBER FEI: Again, it's the same,
9 it's the same one, right? There's not much else
10 to say. I do think it's -- I think from the
11 patient's side it's important, but that's outside
12 of the evidence.

13 MEMBER DORSEY: I agree. Nothing to
14 add for the evidence decision.

15 CO-CHAIR BROOKEY: You guys are going
16 way too easy on me here. Wow. Are you ready for
17 a vote? Go ahead.

18 MEMBER KELLER: I'm actually looking
19 at the nice QCC table on page 36 as I'm going
20 through. I'm noticing that this measure only has
21 one article referenced, whereas the earlier
22 measures had multiple articles referenced. I'm

1 presuming that's because this was a relatively
2 new concept, the article that's referenced is the
3 most recent one.

4 DR. LION: The other differences that
5 the various articles included a variety of
6 detail, level of detail in what was actually
7 included in their intervention and so some
8 authors provided far more detail which allowed us
9 to understand the individual components of the
10 intervention in great detail.

11 MEMBER KELLER: Got you.

12 DR. LION: So in some cases, they just
13 didn't give us enough information in the study to
14 know whether a particular, whether this
15 particular thing was a part of their
16 intervention, so we didn't cite it.

17 MEMBER KELLER: I was going to say
18 because I'm looking at -- conceptually, this
19 seems to be something that's pretty much standard
20 is everything I've ever read, certainly in every
21 guideline I've ever read around care
22 coordination. Interesting. Thanks.

1 CO-CHAIR BROOKEY: Good point. Jon.

2 MR. FINKELSTEIN: I just wondered if
3 the developers want to comment on the denominator
4 issues that are different here. So in this one,
5 it's only if you had contact in the last three
6 months, so someone could have a care coordinator
7 who never calls and then they're not in the
8 denominator of this and the two patients they
9 call they ask about these things and you're 100
10 percent, but you're still doing a terrible job in
11 your system overall. And I understand pros and
12 cons because I can think through why you did
13 this, but I think it's important for you just to
14 tell us about that.

15 DR. LION: One of the indicators that
16 did not make it to you all was actually about
17 having been contacted in the past three months.
18 I forget why we dropped it. But we have that as
19 a separate indicator and it didn't make it
20 through the various hurdles although I forget on
21 which criteria it failed.

22 DR. MANGIONE-SMITH: But you could

1 measure it from the survey. We're just not
2 putting it forward for all of you.

3 MEMBER EDIGER: How is that different
4 than the one that we have?

5 DR. MANGIONE-SMITH: So it's the feed-
6 in measure to this one. It would have been FECC-
7 4, you know, they go from 3 to 5.

8 MEMBER EDIGER: Just whether or not
9 you've been contacted?

10 DR. MANGIONE-SMITH: Exactly.

11 MEMBER EDIGER: And then our question
12 is asking about --

13 DR. MANGIONE-SMITH: Now we're looking
14 at the subpopulation of people who were contacted
15 to see whether these things happen when they were
16 contacted.

17 MEMBER EDIGER: Okay. My comment is
18 I'm a mother of one of these kids and three
19 months seems incredibly short to me. When things
20 are going well, and we're not in the hospital, I
21 am more than happy to not talk to our primary
22 care physician for at least three months. When

1 we go through intense periods where we're being
2 hospitalized all the time and surgery, surgery,
3 surgery, but even with that, three month seems
4 awfully short to me.

5 DR. MANGIONE-SMITH: So interesting
6 that the main evidence we cite said at least once
7 each month and we got the same feedback from our
8 Delphi panel, Family Voices person. She said
9 that would be so irritating. And so it got
10 extended out to three months based on her
11 commentary and that's what, in fact, the working
12 group pointed out to us. Why does the evidence
13 say once a month and you're allowing three
14 months. I explained the same thing to them. But
15 that's what we settled on in the Delphi panel as
16 being a compromise.

17 MEMBER MILLER: This is Marlene. I
18 guess this still gives me pause. I take to bring
19 it back, but you know, the logic of separating
20 out these questions because -- and I even have
21 more concern knowing the missing questions that
22 are in there that would make these other ones

1 make sense is to whether it is really logical to
2 consider these individually.

3 CO-CHAIR BROOKEY: Well, again, I
4 think we decided as a group we're going to move
5 forward with the understanding that this isn't
6 the final, final, that things can be renegotiated
7 later, but I don't think we're going to be able
8 to get through this as just conversation about
9 ten measures all at one time. So I would suggest
10 that we just move forward and then we can always
11 provide input and Maureen provide input about the
12 frequency and things like that. Those can be
13 considered for the future, definitely.

14 Any other comments before we vote on
15 FECC-5? Okay.

16 MS. CHAVEZ: Okay, now voting for
17 evidence for FECC-5 is open on the phone. One,
18 high; 2, moderate, 3, low; 4, insufficient.

19 Seventeen. I'm reading 30, 35. And
20 to those on the phone, the slide is showing 16,
21 all 16 moderate.

22 CO-CHAIR BROOKEY: It's busted, okay.

1 So are we not going to be able to do this
2 electronically? Should we do it manually?
3 Right, now that we've kind of messed this one up,
4 don't we have to go manual?

5 MS. CHAVEZ: Should we just go ahead
6 and do this manually until you guys work it out?

7 DR. MANGIONE-SMITH: For dash 5.

8 DR. NISHIMI: So this is for FECC-5
9 and high, moderate. So that's 18 moderate. Low,
10 five. Insufficient, one.

11 Okay, so it's evidence for FECC-5, 0,
12 high; 18, moderate, 5, low; 1, insufficient.

13 CO-CHAIR BROOKEY: Okay, we can move
14 forward to FECC-7, care coordinator assisted with
15 specialist service referrals. And the leads are
16 Karen and Lauren And Lauren, I believe, is still
17 on the line.

18 MEMBER DORSEY: Yes. So I think the
19 go-to study that we've been talking about,
20 there's not really anything new to say about the
21 evidence supporting this piece. I would say that
22 the developers added an explanation of a few

1 other pre-post design studies that talk about
2 utilization which I think is the logical outcome
3 associated with this particular component of the
4 measure which is being connected with appropriate
5 specialty referral. So they do add that to the
6 sort of go-to study we've been talking about
7 which I think is important.

8 ***PART 3 Section C*** 2:40:33

9 CO-CHAIR BROOKEY: Lauren, anything to
10 add?

11 MEMBER AGORATUS: Yes. I just wanted
12 to add we had the same discussion on the three-
13 month interval which was clarified that it was
14 changed because of the Delphi review panel, and
15 also there was a comment on clarification of
16 assistance with appointments also includes
17 complex care scheduling, which also showed up in
18 the comments under validity, and just a general
19 comment that the body of evidence was weak.

20 CO-CHAIR BROOKEY: Any other comments
21 or questions?

22 MEMBER MOYER: This one strikes me as

1 being -- this actually has two things in it. It
2 has did they help you with getting appointments
3 and were they successful at getting you
4 appointments? So if your child with complex
5 healthcare needs has autism, and they live in the
6 city that I used to live in, there's no way to
7 get an appointment in three months. You're lucky
8 to get one in 12 months. And that's if you know
9 somebody. So I'm wondering whether conflating
10 somebody helping you get appointments and getting
11 appointments means that a parent who is trying to
12 answer this wouldn't know what the right answer
13 was -- wouldn't be able to reflect their
14 experience.

15 CO-CHAIR BROOKEY: Can you read the
16 question?

17 DR. LION: So the question itself asks
18 -- so first it goes through and describes what
19 specialists are. And it says, during the last 12
20 months, did the main provider tell you that your
21 child needed to see a specialist? If you said
22 yes, you moved on to the next question which was,

1 did the person who helped with managing your
2 child's care contact you to make sure your child
3 got an appointment to see a specialist? And the
4 possible answers were never, sometimes, usually,
5 and always.

6 DR. MANGIONE-SMITH: This was
7 operationalized both as a survey measure and a
8 medical records based measure. I think the
9 three-month time window was retained for the
10 medical records based measure, but it was not
11 retained in the question on the survey for
12 parents.

13 CO-CHAIR BROOKEY: Is everyone clear
14 on that? Questions? Okay, if not, let's move
15 forward on FECC-7.

16 MS. CHAVEZ: Okay, voting for FECC-7
17 is now open. Evidence. 1, high; 2, moderate; 3,
18 low; 4, insufficient. Twenty, 23, 24. Zero
19 voted high; 14 voted moderate; 7 voted low; 3,
20 insufficient.

21 CO-CHAIR BROOKEY: Okay, so we're
22 moving on to FECC-8: care coordinator was

1 knowledgeable, supportive, and advocated for
2 child's needs. The leads are Lauren and Amy.

3 MEMBER AGORATUS: Okay, this is
4 Lauren. I had two sets of comments. The first
5 under evidence was the same as under the previous
6 measure, which is body of evidence was weak. And
7 then there were several comments under validity
8 specifications. It's unclear why no ICC and
9 Spearman-Brown were reported for this measure.
10 Is it also because of sample size?

11 Another comment, not comfortable with
12 saying this clearly demonstrates reliability
13 because of internal consistency alpha for the
14 sub-items. And also these questions are ideal
15 for test/re-test reliability, but this was not
16 done and would have been a better assessment of
17 reliability. And then the last comment whether
18 this should be evaluated separately just on
19 reliability grounds. That's all I have.

20 CO-CHAIR BROOKEY: Great. Amy?

21 MEMBER HOUTROW: All right, so as you
22 guys are aware, it followed that same RCT, but

1 unspecific to that is direct advocacy for needed
2 care which is a component of this question which
3 is whether they're knowledgeable, supportive, and
4 advocate for the child's needs. And so there is
5 potentially a little more specificity from the
6 RCT, related to that one of the three aspects of
7 this question.

8 FECC-8 does hit on a number of
9 different areas and I think that as we think
10 about it kind of throughout, we need to be
11 considering that it hits on a number of different
12 concepts, and it also requires that they are
13 thinking yes to each one of these to get a
14 positive response. But basically the evidence,
15 similar to the ones before, is that main RCT and
16 some additional studies.

17 CO-CHAIR BROOKEY: If you look at 8,
18 you might presume they would have answered yes to
19 8 as well as 7, depending on the way they
20 interpret the question. Eight may be a better
21 measure than 7, looking at the two side by side.
22 That's my question. Yes, Jon? Use your mic.

1 MR. FINKELSTEIN: It's warming up.
2 There it goes. So 8 is the one where I'm really
3 concerned about the denominator because I like
4 it, so that these kids should have a care
5 coordinator who is knowledgeable, supportive, and
6 advocates, seems like the denominator should be
7 the kids. And you shouldn't be able to score 100
8 percent on this because you don't provide care
9 coordination services, except to a subset. It's
10 kind of like FECC-1 with a little more
11 specificity than I like, if you had that
12 denominator. So I personally don't see -- I
13 think it has to be interpreted with a denominator
14 of children. I wonder if the developers have a
15 special reason for doing it this way.

16 DR. LION: We considered both
17 approaches and we were concerned that essentially
18 going through, because so many of the subsequent
19 measures build on that first measure, we were
20 concerned about essentially repeatedly penalizing
21 a provider group, a health plan, etcetera, for
22 the same initial fault of not providing a care

1 coordinator. And so we thought this would
2 provide us with, sort of, additional detail and
3 specificity of again exactly where the problem is
4 arising in order to be able to better hold people
5 accountable and facilitate improvement
6 activities.

7 CO-CHAIR BROOKEY: Amy.

8 MEMBER HOUTROW: So to Jon's point, I
9 think that's an important one. So what are the
10 activities of the care coordinator to do? In
11 their mapping, the developers have provided that
12 this question relates to collecting information,
13 synthesizing information, sharing plans,
14 executing plans, and determining where failures
15 occur, which is basically almost everything that
16 they set out to be important in their concept
17 mapping. And so I think, Jon, you're making a
18 very strong and valid point, that this is kind of
19 the essence of what we meant when we mean care
20 coordination.

21 CO-CHAIR SUSMAN: I'm getting really
22 uneasy, though, that we're mixing up all these

1 data points with discussion around evidence. I
2 see that there's very little evidence in this.
3 It all ties to one RCT where they've amalgamated
4 all these elements together and yet, we're
5 disaggregating this by element. So to be able to
6 say that this one has high level of evidence or
7 any of the others or even moderate level of
8 evidence, I just feel very uncomfortable with it.
9 But obviously, we do need to vote with each of
10 these.

11 I just have a hard time parsing out
12 each one and then saying well, this element is
13 important. This element -- and it seems we've
14 sort of taken the whole gemish and we have a
15 fruit cocktail here.

16 CO-CHAIR BROOKEY: I just want to make
17 sure I understand Jon's point. Are you
18 suggesting that we mush 1 and 8 together or --
19 I'm just trying to understand exactly --

20 MR. FINKELSTEIN: You can't talk until
21 it turns red, which is ironic. It should be
22 green. So what I'm -- so as we get to the end

1 and I agree with Jeff, this business of the
2 evidence for each one, and in response to
3 Marlene's comments, I could see us as a group
4 saying there are a few of these that people
5 really should today in 2015 be held accountable
6 for and others that aren't ready for that level
7 of accountability.

8 And if you ask me, and I know this
9 isn't the way the developers have framed it, I
10 would today make people accountable for these
11 kids having a care coordinator who is not
12 knowledgeable, supportive, and advocates. And
13 that, to me, would it be an umbrella metric I'd
14 be comfortable with. But I understand we're
15 parsing right now, but we may at the end get to
16 that.

17 And just to the point that Casey made,
18 I think you do penalize if someone isn't
19 providing a service, you penalize them for not
20 providing a service. You then don't give them
21 credit for doing it well on the small number of
22 times that they do it. You keep penalizing them.

1 CO-CHAIR BROOKEY: So to be clear
2 again, 1 and 8 should be really 1 in a way
3 because it's not adequate to say you have a care
4 coordinator. They should be doing all these
5 things. I think that's what you're saying. And
6 I think no one would disagree with that. Any
7 other comments about this particular measure?
8 Carol?

9 MEMBER STANLEY: Do you mind reading
10 the exact question?

11 DR. LION: Sure. So it's a series of
12 questions. The first is: in the last 12 months,
13 did the person who helped you with managing your
14 child's care know the important information about
15 your child's health and care needs? Would you
16 say yes, definitely; yes, somewhat; no. And then
17 there's also don't know and refused options.

18 In the last 12 months, did the person
19 who helped you with managing your child's care
20 seem informed and up to date about the care your
21 child got from other providers? And again
22 options were yes, definitely; yes, somewhat; or

1 no.

2 And then In the last 12 months, did
3 the person who helped you with managing your
4 child's care support your decisions about what is
5 best for your child's health and treatment? Yes,
6 definitely; yes, somewhat; or no.

7 And I believe this one also: In the
8 last 12 months, did the person who helped you
9 with managing your child's care help you to get
10 appointments to visit other providers?

11 CO-CHAIR BROOKEY: Which was the
12 previous question, in a way.

13 DR. LION: Sorry, and there's another.
14 So for a few of these, we had -- for the A, B,
15 and C subsections, we had a couple of component
16 questions that also --- in the operationalization
17 of these particular questions and going through
18 the cognitive interviews, we couldn't just ask
19 families did the care coordinator -- did the
20 person who helped you advocate for the child's
21 needs, we actually needed to sort of parse out
22 what that would look like.

1 And so -- sorry, another component of
2 it was, in the last 12 months did the person who
3 helped you with managing your child's care help
4 you to get special medical equipment your child
5 needed like a special bed, wheelchair, or feeding
6 tube supplies? So getting help to get
7 appointments and getting the special equipment
8 was part of advocating for the child's needs.

9 CO-CHAIR BROOKEY: And there's an N/A
10 response in there?

11 DR. LION: Yes, for all of those.

12 CO-CHAIR BROOKEY: Okay.

13 CO-CHAIR SUSMAN: How did you end up
14 operationalizing the scoring of all that?

15 DR. MANGIONE-SMITH: So it is. Like
16 she was suggesting, we took a construct like
17 advocates for the needs of your child. And when
18 you go to cognitively interview, you find out
19 people have no idea what you're talking about
20 when you say that. So then we say well, we mean
21 like -- so do you understand when I say if I ask
22 you did that person help you to get appointments,

1 and help you to get services you needed, and
2 equipment you need? Oh, yes, yes. That all
3 makes sense, right?

4 So then in building the survey
5 questions to try to get at that construct, we end
6 up with these two different sub-questions, and if
7 they answered -- it was top box scoring, so if
8 they answered yes, definitely, okay, then they
9 passed that subpart of that construct. Okay,
10 advocates for child was help me get appointments
11 and help me get equipment and other services that
12 I needed right? So they would have gotten, they
13 would have had to say yes, definitely to both of
14 those to get 1.0 on that subpart of the measure.
15 And then there's two other subparts, is
16 knowledgeable. That was captured in one question
17 or two?

18 DR. LION: That was also two.

19 DR. MANGIONE-SMITH: So that was
20 knowledgeable was captured in two of the
21 questions, 5a and 5b. Supports the caregiver was
22 captured in one question, 5c. So you get partial

1 credit in the ones that have two subparts. You
2 get 100 percent in the one that only has one
3 subpart. And then we roll it all up.

4 If we can go to the specifications of
5 exactly how it scored, but it's essentially --
6 there's a lot of room for partial credit in
7 there, right? So you can for any question or any
8 construct that had two subparts, you can get 50
9 percent, right? For the one that only has one
10 question, it's 0 or 1. And then you roll up what
11 your individual scores were on all those subparts
12 to get your score on the measure.

13 CO-CHAIR BROOKEY: Which is also why
14 it makes more sense to be a composite instead of
15 having a stand-alone measure.

16 DR. MANGIONE-SMITH: It is a composite
17 measure.

18 CO-CHAIR BROOKEY: It is a composite
19 within one measure.

20 DR. MANGIONE-SMITH: Exactly.

21 CO-CHAIR BROOKEY: Kevin.

22 MEMBER SLAVIN: How does a don't know

1 get scored? What happens with those answers
2 because if there's a question and then there's a
3 composite underneath of two questions that leads
4 to that, somebody could answer yes on the first
5 question and then don't know on the next two. So
6 how does that all get kind of rolled together?

7 DR. LION: So we only scored measures
8 for which we had complete information, so if
9 somebody skipped, refused, or said don't know,
10 essentially we dropped them from that measure,
11 because we did not feel that it was fair to hold
12 the practice or providers accountable for
13 something that a parent may actually legitimately
14 not know whether someone was working behind the
15 scenes to help make something happen.

16 DR. MANGIONE-SMITH: Just to be clear,
17 right now we're still talking about the evidence.

18 CO-CHAIR BROOKEY: Right. So no one
19 else has asked, so let me just ask in terms of
20 literacy levels, in terms of health literacy, was
21 that diligently addressed during the creation of
22 the tool, understanding that 50 percent of our

1 population, 60 percent in L.A. are health
2 illiterate?

3 DR. MANGIONE-SMITH: Right, and I
4 think if you look at our mode results, you'll see
5 that we've got the best response rate in our
6 mixed mode which was mailed, followed by phone,
7 and the people who were in the phone part of that
8 mix mode tended to be people who were either low
9 English proficiency or minority. So I think that
10 tells us pretty clearly -- and also of lower
11 education levels -- so that tells us pretty
12 clearly that those are people who received the
13 mailed survey and were not comfortable answering
14 it and returning it. So I think even though we
15 went for a sixth grade reading level, and we did
16 cognitive interviewing and all of that, there
17 were people who were not able to complete it as a
18 written survey.

19 CO-CHAIR BROOKEY: Any other questions
20 or comments? I know we're struggling with this
21 going through one measure after the other.
22 Again, I just don't see an alternative, so if we

1 can just continue to go through these. We're
2 just asking about evidence right now. Are we
3 ready to vote? Do you remember which measure
4 we're on?

5 MS. CHAVEZ: Okay, voting for evidence
6 for measure FECC-8 is now open. One for high; 2,
7 moderate; 3, low; 4, insufficient. Thirteen, 21,
8 22, 23, 24. Zero voted high; 19 voted moderate;
9 3 for low; and 2 for insufficient.

10 DR. NISHIMI: So for 8 that -- I just
11 want to note for the record that on 7 that was in
12 the gray zone, so we'll continue to discuss it,
13 but did need to note that for the record.

14 CO-CHAIR BROOKEY: All right, we're
15 moving on FECC-9, appropriate written visit
16 summary content. I believe this is the last one
17 that was primarily based on the one RCT, but
18 there are other papers as well. I believe Amy
19 and Jim are going to be commenting on this
20 particular measure.

21 MEMBER HOUTROW: Yes, so this
22 actually, 9 is whether or not there was an after-

1 visit summary which included a problem list, a
2 current medication list, drug allergies,
3 specialist involved in care, planned follow-up,
4 and what to do related to problems from the
5 outpatient visit. And this one used evidence
6 from not the RCT, but the AAP consensus statement
7 and Palfrey study in 2004 evaluating a medical
8 home model with an N of 117, which was about a
9 written care plan which may or may not be the
10 same thing as an after-visit summary. And so
11 that came up in our discussion of what this
12 actually was.

13 We also discussed how this relates to
14 the expectations from Medicaid Meaningful Use,
15 which this is more encompassing than an after-
16 visit summary from Medicaid Meaningful Use. And
17 in our topic of discussion as a group, we talked
18 about how this was different than a care plan and
19 how that -- there was a general lack of evidence
20 related to this question because it's actually
21 not the same thing as a care plan.

22 CO-CHAIR BROOKEY: Go ahead.

1 MEMBER BOST: The only thing I would
2 add is that it's scored never, sometimes, or
3 always on each of the six components. And as Amy
4 said, most of the concern was around: are these
5 the right six?

6 CO-CHAIR BROOKEY: Any other comments
7 or questions? None?

8 MEMBER KELLER: You mentioned this,
9 but I wasn't clear on the outcome. How do these
10 things line up with meaningful use? How do these
11 line up with the requirements for meaningful use
12 after visit summary?

13 MEMBER HOUTROW: Meaningful use
14 includes these things, but this includes more
15 than what meaningful use says.

16 MEMBER KELLER: It's more than
17 meaningful use. Thank you.

18 CO-CHAIR BROOKEY: Questions,
19 comments? Ready to vote? Okay.

20 MS. CHAVEZ: Okay, voting on evidence
21 for FECC-9. One, high; 2, moderate; 3, low; 4,
22 insufficient. Open. Sixteen, 22, 24. Zero

1 voted high; 11, moderate; 11, low; 2,
2 insufficient. This puts this in the gray zone.

3 CO-CHAIR BROOKEY: So we keep going,
4 we keep going forward. Okay. So are we up to 14
5 now? Is that right? Okay, FECC-14 is a little
6 bit different: healthcare provider communicated
7 with school staff about child's condition. And
8 we have Marlene, Ricardo, and Sue are going to
9 comment.

10 MEMBER QUINONEZ: I can go first. So
11 this one is different than the others because
12 it's supported by just a couple of studies and --
13 sorry, one study, that looked at kids with
14 traumatic brain injury. And better outcomes if
15 -- or perceived better outcomes by the authors if
16 they had a communication with the school and if
17 they transitioned back to school with good
18 communication from the providers. So the
19 evidence basis for this is fairly weak, almost
20 consensus basis, based on one paper.

21 MEMBER MILLER: This is Marlene. I
22 would completely agree with that. It's very

1 problematic to me that this is one study with
2 traumatic brain injury where you could see -- the
3 language of the measure goes on to talk about
4 exact educational impact of the child's condition
5 and it makes sense in traumatic brain injury, but
6 it may not make as much sense for the whole
7 myriad of other chronic conditions. And so it
8 seemed this is a very, very large extrapolation
9 with a TBI study involving 66 kids, so all kids
10 with all chronic disease to warrant this level of
11 communication with the details as specified in
12 this measure.

13 MEMBER KONEK: There was additional
14 information asked for on the call, although I
15 wasn't actually participating on the call, I was
16 listening. And they did come through with some
17 additional information, an article by Weil about
18 school reentry after cardiac transplantation; one
19 by Hart which was a 2015 systematic review of 10
20 qualitative studies emphasizing the importance of
21 communication, and also they cited the AAP
22 Medical Home Policy of 2002 which basically says

1 that this is communication between medical home
2 and the school is very important. So there was
3 additional. Some of it, there was a systematic
4 review, so that was something that wasn't there
5 for the initial call, but that was sent to us on
6 the 24th which was right before Thanksgiving.

7 CO-CHAIR BROOKEY: Right, that's very
8 helpful. Maureen?

9 MEMBER EDIGER: To me, this just
10 sounds like something else that parents are going
11 to have to coordinate, because ideally your
12 medical professionals are talking to the school,
13 but in reality it's going to be the caregivers
14 and the parents that are having to facilitate
15 that so it can get checked off. And I think
16 requiring it just might add another layer of
17 burden or complication to families.

18 CO-CHAIR BROOKEY: Any other? Go
19 ahead.

20 MEMBER BRISTOL-ROUSE: I would just
21 add from the parent perspective too, having a
22 child with special healthcare needs that as we

1 were kind of transitioning out of services I
2 wouldn't have -- I was trying to downplay with
3 the school system like to help normalize and move
4 into that space. And so that's something as a
5 parent I would have wanted to solicit from my
6 provider to connect with the school. And I know
7 that's not appropriate for every family, but just
8 from my experience.

9 CO-CHAIR BROOKEY: And speaking as a
10 pediatrician, I think there's a few in the room,
11 we wouldn't do that without the parent's
12 permission and probably without the parent asking
13 us to do that. So it's just to say from a
14 logical perspective, although it's very helpful
15 what you stated in terms of the support for this
16 practice.

17 MEMBER BRISTOL-ROUSE: Right.

18 CO-CHAIR BROOKEY: It isn't just the
19 provider, it's the parents and the provider,
20 right?

21 MEMBER KONEK: Right. I do have
22 another comment. The thing that I -- when I

1 looked at this more closely it emphasized that
2 what the coordinator can bring to the school is
3 information perhaps and of course with the
4 family, perhaps, but to -- about whatever their
5 condition is or chronic condition, complex
6 condition is, it results in their ability to
7 learn. It's not just how they're doing
8 physically, it's a lot more than that. And that,
9 I think, goes into the individual education plans
10 and things like that. I learn more by reading
11 those things.

12 CO-CHAIR BROOKEY: So again, we're
13 talking -- go ahead.

14 MEMBER AGORATUS: Hi. I'm also a
15 parent of a child with five life-threatening
16 conditions and autism, just to keep things
17 interesting. And one of the tools that we
18 utilize at the Parent Training and Information
19 Centers is an individual health plan, which is an
20 addendum to the individual education plan. So
21 yes, while it would be helpful for a pediatrician
22 to do this, it may not be necessary if everything

1 is in writing and it's being followed.

2 CO-CHAIR BROOKEY: Great. Great
3 point. From the developer's standpoint, anything
4 you want to add? We are talking just about the
5 evidence right now?

6 DR. MANGIONE-SMITH: The only concern
7 that I would put out there for people is I think
8 we have incredibly savvy parents around the
9 table, and on the phone and I would worry a
10 little bit about parents who cannot advocate for
11 their child in the same way as what we're
12 hearing.

13 CO-CHAIR BROOKEY: All good points.
14 Go ahead, David.

15 MEMBER KELLER: I would say similarly
16 that part of our routine care coordination
17 process, we've been piloting care coordinators in
18 our office since 1997, so we've been doing this
19 for a while. When we get a family hooked up with
20 our care coordinator, one of the first things we
21 do is get permission to talk to school as -- we
22 never do it without letting the family know that

1 we're doing it, but we always have an up-to-date
2 consent form so that we can have that
3 communication. So I do think this is really
4 important.

5 I also think it hasn't been studied
6 well. I just took a look through the studies
7 that they sent and of course, they were in very
8 specific instances of brain trauma and cardiac
9 disease. There's some work on communicating
10 around asthma that I think probably has gone a
11 little bit further than most, but the area of
12 communication with the school has been poorly
13 studied, even though having the school as part of
14 the team when you're dealing with a child with
15 special -- with medical complexity is
16 acknowledged by just about everyone. So I agree
17 that there is very little evidence, but there is
18 certainly a lot of clinical juice behind this.

19 CO-CHAIR BROOKEY: Martha?

20 MEMBER BERGREN: So one of the things
21 I didn't mention before is that prior to becoming
22 a faculty member, I was a school nurse in four

1 states. And the importance of the school
2 understanding the child's health conditions and
3 the program of care is essential. And if you
4 don't have it, you are flying in the dark.

5 I agree that those of you around the
6 table and on the phone are very savvy parents who
7 can probably case manage your own kids without
8 the assistance of the school, but often it's the
9 school that's the case manager and is the only
10 person who's talking to every specialist and the
11 primary care providers.

12 So I'll take it upon myself as having
13 previously worked for the National Association of
14 School Nurses that we need to up the ante on the
15 evidence in this area. I will commit to that,
16 but I really do think it's essential. And I
17 agree with David that it really is on the primary
18 care provider in the school to initiate that
19 consent, the authorization to exchange
20 information, so that all the care that's going on
21 in the school is communicated with the primary
22 care provider, and the primary care provider's

1 goals for that child, but both health and
2 educationally, are known to the school.

3 CO-CHAIR BROOKEY: Karen.

4 MEMBER DORSEY: I was just going to
5 say that in a case like this where we imagine the
6 entire spectrum from this kind of requirement
7 being intrusive for some families and seen as not
8 helpful, and being essential for other families,
9 this may be an area where a stratified measure
10 may be more appropriate. And I think we don't
11 have the evidence to even think about how to
12 stratify it yet. So I concur that it's
13 important, but not necessarily important in the
14 same way for all families. And so really that
15 kind of nuance needs to be better explored.

16 MEMBER BRISTOL-ROUSE: And I think
17 that's my response, because I absolutely hear
18 that those of us at this table are anomalies,
19 very much, in many ways, but I'll own that,
20 Maureen, but I think it is essential for some
21 families. So I think it's what the -- when
22 you're talking about making providers accountable

1 it's a different level and so what is the opt
2 out? Are you getting consent before every kind
3 of interaction you would have with the school
4 instead of me saying no, I don't want it, and
5 then my provider getting dinged because they
6 didn't do it? So I think that's where the issue
7 lies.

8 CO-CHAIR BROOKEY: So we have a few
9 flags up. Are there new comments, then go ahead.
10 Otherwise, we will move towards a vote. Maureen?

11 MEMBER EDIGER: I don't want to be
12 misunderstood, but I don't think that this is a
13 great idea. I just think that it's not helpful
14 to the provider that it's something else that
15 they are now accountable for. And absolutely
16 should families or kids -- really, the kids that
17 need that communication, absolutely, it should be
18 there. I just don't think this is the right
19 context for it.

20 CO-CHAIR BROOKEY: I think there are
21 some really good comments made. We're going to
22 vote on the evidence for this measure which

1 sounds like it was fairly low. And so the
2 question would be whether we can even actually
3 vote this as high, or whether it's going to turn
4 out to be at most a moderate. Is that an
5 individual decision or can we make the decision?

6 DR. NISHIMI: It was not based on a
7 systematic review.

8 CO-CHAIR BROOKEY: Correct. So I
9 think the highest should be a moderate in this
10 case. Okay.

11 MEMBER KELLER: This was based on a
12 systematic review conducted, as was everything
13 else here. It's just that the systematic review
14 didn't find anything, which is different.

15 CO-CHAIR BROOKEY: All right.

16 DR. NISHIMI: The evidence supporting
17 it is a single paper, derived from it
18 systematically.

19 MEMBER KELLER: Derived from that
20 overall -- the same systematic review they did to
21 try and back up everything else they did. So I
22 don't think we can say they didn't do a

1 systematic -- the fact that a systematic review
2 finds no evidence --

3 DR. NISHIMI: That's fair.

4 CO-CHAIR BROOKEY: So you can
5 individually decide whether or not it was
6 sufficient and score it a high. Is that fair?
7 So if you feel the systematic review was thorough
8 enough to score it a high, go for it, otherwise
9 you can score it a moderate, low, or
10 insufficient. And then if it's insufficient, we
11 can go further. So let's go ahead and vote on
12 this measure.

13 MS. CHAVEZ: Okay, now voting on
14 FECC-14 for evidence. One, high; 2, moderate; 3,
15 low; 4, insufficient. Thirteen, 22, 24. Okay,
16 zero voted high; 2 voted moderate; 15 voted low;
17 7 voted insufficient. This does not pass
18 evidence.

19 DR. NISHIMI: So when we go to the
20 next criterion, which is gap, we will not
21 consider this.

22 CO-CHAIR BROOKEY: Okay, again, we're

1 changing the topic a little bit on FECC-15, the
2 caregiver has access to medical interpreter when
3 needed. And the leads are Lauren and Jim.
4 Lauren, would you like to go first?

5 MEMBER AGORATUS: Sure. Under
6 evidence, I had a general comment that there
7 needs to be more on cultural competency, not just
8 professional translation. And another comment
9 that there was no grading system. There were
10 concerns in other areas as well. Another general
11 comment where health disparities should be
12 addressed in all measures, not just this one.
13 Concerns about sample size and reliability and
14 validity, which I guess we'll get to later.
15 That's it.

16 CO-CHAIR BROOKEY: Thank you.

17 MEMBER BOST: Just briefly, there were
18 a lot more studies associated with this evidence-
19 based assessment, but they were not all about
20 complex kids and that the item is actually scored
21 always, sometimes, never -- always, usually,
22 sometimes, and never.

1 CO-CHAIR BROOKEY: Okay. Any comments
2 or questions about the evidence for this measure?
3 Kevin?

4 MEMBER SLAVIN: Does it matter that
5 this is a legal requirement, at least in the
6 state that I practice? If we don't speak the
7 language, we are legally obligated to find
8 somebody to help us interpret, so in my mind it
9 doesn't matter what the evidence says. If you're
10 not doing this, you're practicing outside of the
11 law.

12 DR. LION: While that is certainly
13 true in both my clinical practice and in loads
14 and loads of studies, there's lots of evidence
15 that that does not stop people from not using a
16 professional interpreter to communicate with
17 limited English proficient families. So we know
18 that even though it is, in fact, the law and it's
19 a federal law, people still don't do it.

20 MEMBER AGORATUS: This is Lauren. I
21 have to concur with that. As a bilingual
22 advocate, I hear from Spanish-speaking families

1 all the time and unfortunately, sometimes they
2 use children as translators. And so the medical
3 information isn't even accurate.

4 CO-CHAIR BROOKEY: Or housekeepers.
5 Good point, but I have to agree that it's
6 underutilized. The AT&T line is underutilized.
7 Interpreters are underutilized. I think most of
8 us would concur. Any other questions about the
9 evidence of the measure?

10 MEMBER DORSEY: Sorry, I just wanted
11 to say that this may be one instance to Jim's
12 point where the literature review criteria was
13 too stringent. I mean given that in many, many
14 situations in the healthcare environment, a
15 translation has been demonstrated to be critical.
16 I don't see a reason why we would not extrapolate
17 from that body of evidence to this patient
18 population which even more -- has more of a need
19 for clarity and communication. So I think I just
20 want to advocate that we be a little more lenient
21 in terms of understanding that the entire breadth
22 of the literature probably applies in this

1 instance.

2 CO-CHAIR BROOKEY: Okay, let's vote.

3 MS. CHAVEZ: We're preparing to vote
4 on evidence for -- this is for 15 for those on
5 the phone. 270-15. We're at 18, 20, 21, we're
6 15 24. Five for high; 19 for moderate; 0 for
7 low; 0 for insufficient.

8 CO-CHAIR BROOKEY: Very good. I think
9 we have two more of these to vote on evidence.
10 Do you think we'll finish all the rest of them by
11 3:30? What do you think? The FECC-16 is child
12 has shared care plan. And the leads on this
13 discussion will be -- is Craig here? Craig and
14 Karen.

15 MEMBER KNUDSEN: In terms of evidence
16 on this one, the reviewers found it had pretty
17 strong evidence, actually. There were seven RCTs
18 done on this; three cohort studies, seven case
19 series studies; and two consensus statements, one
20 from AAP. And they all showed better outcomes
21 with shared care plans. So that's pretty much
22 the evidence there.

1 CO-CHAIR BROOKEY: Karen?

2 MEMBER DORSEY: I don't have anything
3 to add.

4 CO-CHAIR BROOKEY: Any comments or
5 questions? Go ahead, David.

6 MEMBER KELLER: So I confess I didn't
7 look up all the studies, so this is a question
8 for the developers. Shared care plan is an
9 interesting concept. We're in the middle of
10 trying to define it in my institution, and it's
11 challenging. How much commonality was there
12 between the definition of a shared care plan and
13 how did you -- in these different studies, and is
14 that reflected in the questions that you actually
15 used for this measure?

16 DR. LION: So we were limited to some
17 extent again by the amount of detail that authors
18 chose to provide. There was some instances where
19 a single study was described in multiple
20 different publications where we could find more
21 details in one of the publications compared to
22 others. There were certainly not enough

1 evidence, enough detail in the descriptions of
2 the shared care plans for us to be able to
3 identify particular aspects or elements of shared
4 care plans. They were more likely to be
5 associated with better outcomes although we
6 certainly tried.

7 In thinking about how to actually
8 conceptualize a shared care plan, we had a number
9 of criteria that needed to be met. It needed to
10 be described as a shared care plan or an
11 individualized tailored to that particular
12 patient and/or family. It needed to be developed
13 by the patient and family in conjunction with the
14 primary care provider or a care coordinator and
15 then shared with a primary care provider. It
16 could also incorporate other providers in a
17 multi-disciplinary team.

18 There was quite a bit of variety in
19 the different studies in who all was involved in
20 the multi-disciplinary teams, or who was being
21 shared with, indeed. But we found a fair degree
22 of variability in how things were described, but

1 we tried to sort of identify the lowest common
2 denominator in terms of a shared plan developed
3 with a patient or family and the PCP or care
4 coordinator.

5 CO-CHAIR BROOKEY: Questions,
6 comments? Go ahead, Ricardo.

7 MEMBER QUINONEZ: So as a recipient of
8 shared care plans often as a hospitalist, I find
9 that a large percent of them are not updated.
10 And so you could argue that that would actually
11 make outcomes worse, since we are likely to put
12 in the -- I mean, obviously, we should ask the
13 family, but sometimes residents will put in the
14 orders for wrong medications, for the wrong dose,
15 etcetera, etcetera. Was there a discussion of
16 adding an updated care plan and what the
17 condition would be? I just see that as an
18 unintended consequence.

19 DR. LION: Fantastic questions. So
20 the way the measure was initially specified, we
21 did actually include a subpart looking at when --
22 if it was not developed in the past year, whether

1 it was updated in the past year. Unfortunately,
2 because -- and this gets some into the
3 performance gap, but because the overall
4 performance on having a shared care plan at all
5 was so low, what -- what we found was -- overall
6 only about 40 percent of kids had one.

7 If you did have one, your performance
8 on the subparts, including being updated in the
9 past year was actually pretty good. So we saw
10 ceiling effects on the subparts, but a very
11 relatively poor performance overall. So we ended
12 up at this point dropping those subparts from the
13 measure, because it didn't seem, at this point,
14 worth measuring, but in the future when shared
15 care plans have better uptake, perhaps.

16 CO-CHAIR BROOKEY: And I'm sure your
17 resident's reconciled medication was 100 percent
18 of the time. Okay, can we move to vote on this
19 one? Alright, sounds like we feel more favorably
20 about this one, so let's go ahead and move to
21 vote.

22 MS. CHAVEZ: Okay, now voting on

1 evidence for FECC-16. One, high; 2, moderate; 3,
2 low; 4, insufficient. Thirteen, 23, 24. Twelve
3 voted high; 11 voted moderate; 1 voted low; and 0
4 for insufficient.

5 CO-CHAIR BROOKEY: Okay, so we're
6 voting on our last one for evidence. This is
7 FECC-17, child has emergency care plan. And
8 according to what my notes are, there was not an
9 empirical evidence review provided. Unless
10 that's changed -- has that changed? Okay, so,
11 developer, go ahead and fill us in on the
12 changes.

13 DR. LION: So following the work group
14 call, we took another look at the evidence and we
15 identified two, in addition to the two AEP
16 consensus statements related to emergency care
17 plans would strongly endorse their use. We found
18 two additional studies. One was -- where is it?
19 So we identified a randomized control trial.
20 However, it had fairly poor follow-up, so it
21 randomized 170 patients with complex congenital
22 cardiac disease to a program of a web-based

1 emergency care plan for the ones who were
2 randomized to the intervention.

3 Unfortunately, 35 percent of the
4 enrolled participants completed both the baseline
5 and follow-up surveys, however, there were
6 approximately even numbers in both the
7 intervention and control groups. And there was
8 an improvement in the intervention group in the
9 parent's perception of emergency care provider's
10 comfort and ability to care for their child.

11 Interestingly, however, the emergency
12 care plans were only accessed in 13 out of 100-
13 ish actual emergency room visits. So it's
14 unclear whether it just improved parent comfort,
15 knowing that it was there, or whether it actually
16 changed the way care was provided.

17 So while it was an RCT, I gave that a
18 level 3 to 4 evidence because of the low follow-
19 up. And then we also found essentially a cohort
20 study describing an intervention with emergency
21 care plans for children with life-threatening
22 asthma. However, there was no clear comparison

1 group identified and so even though they reported
2 decreased hospitalizations and decreased deaths
3 associated with asthma, it was unclear what
4 exactly they were comparing that to. So although
5 it was pitched as a cohort study, I think it was
6 probably more of an expert statement. So we did
7 find some -- a description of a nice program.

8 CO-CHAIR BROOKEY: So mixed findings.
9 Karen and Lauren, do you want to make comments?

10 MEMBER AGORATUS: Sure. I had the
11 same kind of concerns that it was an outcome
12 based that more information was requested on the
13 American Academy of Pediatrics consensus
14 statement which was provided. Again, the comment
15 of no empirical evidence, but that was a draft.

16 Also, that the AAP recommends
17 emergency preparedness for natural disasters in
18 addition to emergency care plans. Also, the last
19 comment was that some of the evidence in adult
20 studies isn't applicable to children. That's it.

21 MEMBER DORSEY: So given the sort of
22 lack of evidence supporting these in this area,

1 you know, I'm thinking about it as something --
2 considering the threshold of whether it's so
3 important to measure that we sort of say it's
4 okay, that the evidence is insufficient. And I'm
5 a little torn because I feel like it's an
6 incredibly important thing, right, that having
7 emergency plan is like one of those high level
8 sort of portability of medical information goals.
9 But I fear what you just said, which is that
10 we're not really that portable yet and that even
11 when we have them in the moment of an emergency
12 we're still not at that place where it's easily
13 accessed, consistently accessed. So that's my
14 thinking on it.

15 CO-CHAIR BROOKEY: Comments? Ricardo?

16 MEMBER QUINONEZ: Just a
17 clarification, so it sounds like from the
18 evidence we should only be voting on insufficient
19 or insufficient with exception?

20 CO-CHAIR BROOKEY: Well, I think we
21 have to determine whether that was a systematic
22 review or not, and if you think it is and it's

1 sufficient, you can vote high or moderate. If
2 you don't buy that that's sufficient, then it
3 would be limited to low or insufficient, but it
4 could still be voted again for with exception.
5 So we'll make it an individual choice as to
6 whether or not this latest information is going
7 to influence your vote. Any other comments or
8 questions? You're all getting kind of tired,
9 aren't you? So let's vote.

10 MS. CHAVEZ: Now voting on evidence
11 for FECC-17. One, high; 2, moderate; 3, low; 4,
12 insufficient. Fifteen, 22, 24. Zero voted high.
13 Three voted moderate. Nine voted low. And 12
14 voted insufficient.

15 CO-CHAIR BROOKEY: That's 50 percent
16 for insufficient. So this does not pass or do we
17 vote on with exception? So this measure will not
18 move forward then. Did we change the rules? Why
19 don't we take a break? We'll look at the rule
20 book. We'll come back in five minutes, and
21 please be back in your seats in five minutes.
22 We'll keep going.

1 (Whereupon, the above-entitled matter
2 went off the record at 3:31 p.m. and resumed at
3 3:40 p.m.)

4 CO-CHAIR BROOKEY: We've huddled about
5 whether we're going to be able to vote for this
6 last measure, for an exception, with insufficient
7 evidence, and the answer is we don't know.

8 So I'm going to ask whether it's
9 reasonable that -- I'm going to ask if it's
10 reasonable that we go ahead and vote, and then if
11 we have to retract it later we will, but I think
12 it's easier to vote now than to have to vote
13 later, since it's fresh on our minds. Does that
14 make sense?

15 So if everybody can get your clickers,
16 and get ready to vote, we're going to go back to
17 the last measure, which was, I think, 17, is that
18 right?

19 And since we have 50 percent
20 insufficient, we're going to go ahead and vote on
21 whether you think the measure is still important
22 enough to move it forward, with exception.

1 So we're going to vote here in ten
2 seconds. So get ready, set, go ahead. Seventeen
3 insufficient evidence, with exception.

4 We're voting on exception.

5 MS. CHAVEZ: Okay, for those on the
6 phone, we're voting on exception. Choices are
7 one, insufficient evidence with exception, two
8 for no exception. Measure FECC 17. I have 16,
9 20, 20, eight seconds, 22, 23.

10 Okay. Okay, so eight voted
11 insufficient evidence with exception, 15 voted
12 for no exception.

13 CO-CHAIR BROOKEY: Okay. And so those
14 of you who missed my earlier comments, we're
15 voting. And we're not really clear if we're
16 allowed to, but if it turns out that we can't
17 vote because of the rules, we'll take this back
18 later. But we just want to go ahead and get the
19 vote in, just because it's all fresh on our
20 minds.

21 Now, we're going to ask the
22 Committee's permission to do a little change in

1 schedule. Just -- so I think we've gotten
2 through the hardest piece of these ten measures.
3 Some of these will not go forward for further
4 voting, but many of the elements of GAP and use
5 and usability and feasibility, we can vote en
6 bloc, in terms of just one vote for all the
7 measures. So the only thing we have to go
8 through for each and every measure will be the
9 reliability and validity.

10 We do have a group here with the
11 Adolescent Measures, the ADAPT, that will not be
12 here tomorrow morning. However, our folks here
13 will be here tomorrow morning, so we're going to
14 ask if we could do --

15 (Laughter.)

16 CO-CHAIR BROOKEY: We're going to give
17 them a -- we're going to give them a nice sleep,
18 to get rested up for tomorrow morning.

19 Is there any objection to postponing
20 the rest of the conversation about these ten
21 measures until tomorrow morning, so we can have
22 the ADAPT conversation now? And we'll do as much

1 as we can do to get through five o'clock, but any
2 objection to that? So if not, let's move forward
3 to Adolescent Assessment of Preparation for
4 Transition to Adult-Focused Health Care. And we
5 have our developers coming to the table.

6 So if you could give us a brief
7 overview. And, again, primarily focused in the
8 beginning, at least, on the evidence for the
9 review.

10 DR. SAWICKI: Good afternoon. I guess
11 we're the last team before you at the end of the
12 day. My name's Gregory Sawicki. I'm a pediatric
13 pulmonologist and health services researcher at
14 the Center for Excellence for Pediatric Quality
15 Measurement, at Boston Children's Hospital,
16 joined today with my colleagues, Doctors Sara
17 Toomey and Mark Schuster, and we represent the
18 team that developed the Adolescent Assessment of
19 Preparation for Transition, or ADAPT Measure.

20 Health care transition is a process by
21 which adolescents and young adults shift from
22 pediatric-focused to adult-focused health care

1 delivery.

2 Multiple guidelines, expert panels,
3 consensus statements, and patient advocacy groups
4 have called on the medical profession to prepare
5 adolescents for developmentally-appropriate care,
6 whether they are changing providers, or staying
7 with the same clinical team.

8 Transition should be planned,
9 purposeful and have the goal of providing
10 uninterrupted high-quality care. The lack of
11 effective transition may contribute to
12 fragmentation of health care and increased risk
13 for adverse health outcomes, particularly during
14 youth adulthood.

15 There is broad consensus that
16 preparation for health care transitions should
17 start in adolescents and involve individualized
18 planning. Transition services are, therefore,
19 key aspects of high-quality care for adolescents,
20 particularly those with chronic health
21 conditions.

22 In a joint 2011 clinical report, the

1 American Academy of Pediatrics, the American
2 Academy of Family Physicians, and the American
3 College of Physicians provided a consensus-based
4 framework for physicians to implement
5 high-quality, developmentally-appropriate health
6 care services for transition.

7 This framework includes
8 recommendations for providers to assess
9 transition readiness, develop a transition plan,
10 and document plans and health records as part of
11 the medical home.

12 Results of a recent randomized study
13 in primary care practices in Washington, D.C.
14 demonstrated that implementing recommended
15 elements of transition preparation improved the
16 quality of care coordination for youth with
17 special health care needs.

18 Other condition-specific studies,
19 including populations of youth with diabetes,
20 cystic fibrosis, and congenital heart disease,
21 have established a link between structured
22 transition efforts and improved outcomes,

1 including better transition readiness and
2 improved engagement in the adult system.

3 Although evidence is emerging to link
4 efforts to improve transition preparation with
5 longer term outcomes, we acknowledge that the
6 level of evidence, currently, is likely to be
7 insufficient at this time, and we believe that
8 our way forward here may be through the exception
9 approach.

10 There is, however, a large body of
11 evidence that, for many adolescents with chronic
12 health conditions, preparation for transition is
13 seriously inadequate.

14 In repeated national survey studies,
15 only a minority of youth with chronic health
16 conditions, or their parents, report having
17 discussed transition with their physician, or
18 having a plan addressing transition needs.

19 As an example, in our development
20 focus groups, we heard, more than once, the youth
21 were only informed of their need to transfer care
22 by administrative staff, rather than their health

1 care provider.

2 We developed ADAPT as part of the
3 Pediatric Quality Measures Program sponsored by
4 AHRQ and CMS. ADAPT is a survey instrument for
5 adolescents ages 16 and 17 years old, in which
6 they report on whether specific aspects of care
7 related to transition preparation occurred.

8 We reviewed the transition literature
9 and conducted interviews with expert researchers
10 and clinicians. Focus groups were then conducted
11 in three U.S. cities, with youth with one or more
12 chronic health conditions, as well as with
13 parents of those with chronic health conditions.

14 From this formative work, we drafted
15 an initial survey and conducted cognitive
16 interviews in English and Spanish in three U.S.
17 cities.

18 We then fielded the survey, by mail,
19 in English and Spanish, in one pediatric hospital
20 and two Medicaid health plans. We received over
21 1,600 surveys and used the data for psychometric
22 testing, composite development, and case mix

1 adjustments.

2 ADAPT consists of 26 questions
3 assessing the quality of transition preparation
4 as reported by youth with chronic health
5 conditions, and generates a score for each of
6 three domains: counseling on transition
7 self-management, counseling on prescription
8 medication, and transfer planning. We have
9 presented evidence that the measure is both
10 reliable and valid.

11 We believe that ADAPT fills an
12 important need for publically-available measures
13 of health care quality for adolescents. It will
14 serve as a valid and valuable tool to assess
15 health system quality and motivate improvements
16 in care delivery. We look forward to your
17 comments.

18 CO-CHAIR BROOKEY: Okay, I believe
19 it's Marlene, Amy, and Kerri. I don't know who
20 wants to start.

21 MEMBER MILLER: This is Marlene. I
22 can start. So it's not -- in terms of the

1 evidence, the report in here, I don't really see
2 that there was a real systematic literature
3 review, there's a couple of quasi-experimental
4 studies that are referenced.

5 But really, there's not evidence, in
6 terms of -- and I think it's really important. I
7 think it's evidence that physician counseling,
8 which is what this survey solely measures -- and
9 that is an intervention, but that will achieve
10 transition readiness.

11 I think it's undoubted that preparing
12 teams for a transition to adult care is
13 important. What there's no evidence for,
14 however, is that provider counseling -- which all
15 the questions on this survey say, did your
16 provider, did your provider, are the ways to
17 achieve that.

18 I mean, I know we're -- in our
19 institution we're looking at things with, you
20 know, the nurse extenders and the -- in
21 simulation, and all other things that aren't
22 necessarily that one provider and are much more

1 longitudinal than just a counseling session,
2 which could mean one of a million things in terms
3 of how long that actually happened.

4 So I was -- I don't think the evidence
5 -- the evidence is insufficient, for sure, it's
6 not low. But more particularly, I didn't really
7 appreciate in the write-up the lack of attention
8 to the fact that this is putting forth an
9 intervention that it's all the providers
10 counseling on this, and that that is -- there's
11 no evidence that that provider, alone, will
12 achieve transition readiness at counseling.

13 MEMBER HOUTROW: This is Amy. Just to
14 give a little bit more context. So this was
15 implemented in a specific age group, 16 to 17,
16 and that came by consensus. And there was a lot
17 of discussion about whether the evidence supports
18 earlier, like the AAP recommends, or potentially
19 later, now that health plans have changed when
20 kids have to transition.

21 And the domains that they were
22 interested in are, specifically, counseling on

1 transition self-management, counseling on
2 prescription medications, and then, transfer
3 planning, so it's three different areas. And then
4 they used a survey of 26 questions to get at
5 those, and so numerators and denominators are
6 important here.

7 The proportion of positive responses
8 on five questions for the counseling on
9 transition self-readiness, the positive response
10 on three questions for medication, and four
11 questions for transition planning.

12 And then the denominator's
13 respondents, who had valid responses to that --
14 and in the way that this is intended to be used
15 could be at the individual practice level, or at
16 the health plan level. I think also something
17 for us to consider when we consider the evidence.

18 Some of the other concerns that were
19 brought up about -- in addition to, if the
20 provider does that, does that lead to a specific
21 change in the patient, whether they feel more
22 comfortable, whether their outcomes are

1 different, in addition that this may not capture
2 enough regarding specific groups of individuals,
3 who may be in high need of transition services
4 but may not be able to participate in the
5 transition readiness in this way, such as
6 children with developmental disabilities, who
7 couldn't even answer a survey like this, nor
8 could they engage in a -- necessarily, in a
9 dialogue with their provider about those aspects
10 of care.

11 So I think in that -- Marlene's point
12 about, is this -- if we measure something that a
13 provider does, is there evidence that that will
14 change something at the patient level is a key
15 point.

16 CO-CHAIR BROOKEY: Kerri.

17 MEMBER FEI: I don't have a lot to
18 add, except the fact that this is a patient-
19 reported outcome measure and it is measuring how
20 ready these kids feel to start taking care of
21 themselves, and I think that's important.

22 And I understand the back and forth

1 about whatever the provider does, does that
2 affect how they feel? As this stands, it's like
3 a survey measure. And given that, with the
4 evidence, when we look at the algorithm, it's
5 going to be a pass/fail.

6 It's not going to be -- it either will
7 pass, or it won't pass. So we won't go down the
8 list, am I correct?

9 They say it at the top box. Because
10 this is a -- it's a patient-reported outcome
11 measure.

12 CO-CHAIR BROOKEY: Which is what we're
13 going to be voting on, and so I think it's
14 important to ask the question, again, just to be
15 clear in everyone's mind, about the denominator.

16 Because I think, probably, if we go
17 around the room, everyone's going to be
18 challenged with the 16/17. And, can we speak a
19 little bit more to that, so that we know what
20 we're voting on? So, Jenny.

21 MEMBER MOYER: My question, really, is
22 about the previous comment. This did not strike

1 me as a patient-reported outcome, this is a
2 survey of the patient to see what their provider
3 did. Did your provider have you talk to this
4 provider? Did this provider talk to you?

5 And those things that -- if the change
6 that we're looking for is the provider changing
7 their behavior, then this is not a
8 patient-reported outcome, it's a survey of the
9 patients, to find out how they assess their care.

10 MEMBER FEI: I don't know if you guys
11 want to speak to that? I mean, I view it as any
12 type of patient -- almost like a patient
13 experience measure.

14 DR. SAWICKI: Well it is a patient
15 experience measure.

16 MEMBER FEI: Right.

17 DR. SAWICKI: And whether that's
18 considered a patient-reported outcome versus a
19 patient survey. I mean, this is a -- you're
20 correct that this is a survey asking an
21 adolescent to report on what their provider has
22 told them, or counseled them about, so it is a

1 patient experience measure.

2 MEMBER FEI: It was submitted as a
3 patient-reported outcome measure in the
4 materials, though, just so --

5 CO-CHAIR BROOKEY: Does everyone
6 understand the implication of that? So if we say
7 that it is patient-reported outcome, we only have
8 a yes or no vote. And so if we don't believe it
9 is, it can go down the path of going from
10 insufficient evidence and we can actually go for
11 exception.

12 But if we do say yes, it's a
13 patient-reported outcome, then it's either going
14 to pass or not pass. So that's why the pathway
15 will be different, depending on what we consider
16 this to be.

17 So is there any objection to moving
18 this forward as a patient-reported outcome
19 survey? I've heard one objection.

20 Any other comment?

21 MEMBER FEI: And here's the thing, I
22 don't know that -- can we decide that. It's the

1 developers that submitted it that way and if --
2 I'm not, that's where, maybe, we need NQF's --
3 that we need staff involvement here, because I'm
4 not sure that we can tell them what to do. I
5 don't think that's the right way to go.

6 CO-CHAIR BROOKEY: I think you can
7 just go by what they have on the screen, what
8 they've determined it to be, so --

9 MEMBER THACKERAY: Yes, if I'm reading
10 the box correctly, patient-reported outcome, or
11 patient-reported experience, both follow the same
12 pathway.

13 CO-CHAIR BROOKEY: Right.

14 MEMBER MOYER: I'm looking back at the
15 FECC that is a patient-reported measure. That's
16 a patient survey to find out whether things
17 happened.

18 So I think this one and that one are,
19 conceptually, exactly the same and should be
20 handled the same way.

21 CO-CHAIR BROOKEY: So let's see, Jeff.

22 MEMBER SCHIFF: I just had a couple of

1 questions. This is mail and survey only, so I'm
2 wondering if there's a -- if you have any
3 experience with how many, were they distributed
4 by mail to -- for dispense?

5 DR. SAWICKI: For --

6 MEMBER SCHIFF: It's a little unclear,
7 as to what they --

8 DR. SAWICKI: For our field test, the
9 surveys were sent, by mail, to families with an
10 explanation and cover letter, to ask the families
11 to have the youth complete the survey.

12 MEMBER SCHIFF: Okay. For foster care
13 -- you said there was an exclusion for court law
14 enforcement. Foster care was included, or not?
15 Was that included in the court?

16 DR. SAWICKI: I don't recall if we had
17 that come up at all, with the -- the patients
18 were identified in one of two ways. One through
19 administrative health plan data, and the second
20 was through a clinical program giving us
21 information about their patient panels.

22 MEMBER SCHIFF: Okay. In English

1 only?

2 DR. SAWICKI: English and Spanish.

3 MEMBER SCHIFF: Okay.

4 CO-CHAIR BROOKEY: So we're going to
5 ask Karen to make some comments about the
6 pathways here, for these two sets of measures,
7 can you just go ahead and speak to that for us?

8 MEMBER JOHNSON: So the way, I think,
9 we -- oh. I'm sorry. I'm Karen Johnson. I'm
10 one of the Senior Directors here at NQF. The way
11 that we would handle this measure is we would
12 consider this a PRO -- PRO-PM, a measure. It is
13 a patient experience measure, so it would go down
14 that pathway of the green box.

15 But be very clear, by doing this,
16 we're not looking for the kind of evidence that
17 you were looking for for the earlier measure, so
18 we're not interested in quantity, quality,
19 consistency.

20 What you're wanting to know here is
21 whether there is something that providers can do
22 to affect this outcome or this patient

1 experience. So that would be -- that's why you
2 have a yes or no there.

3 CO-CHAIR SUSMAN: I have a fundamental
4 concern that, I think, Virginia already talked
5 about, which is, this seems exactly like the FECC
6 measures and we've treated it very much
7 differently. It just doesn't compute here, from
8 a consistency and a reliability standpoint.

9 MEMBER JOHNSON: So the measure that
10 you just talked about, the FECC measure, each of
11 the individual performance measures within, even
12 though it was off of one survey, each of those
13 measures were process measures. Right. Did you
14 have a care coordination? Did they do this? Did
15 they do that? Each of those are process measures
16 and those go down the QQC pathway. These are not
17 process measures. They're not asking them, did
18 the provider do something, this is an experience
19 measure.

20 MEMBER MOYER: And as I read --

21 CO-CHAIR SUSMAN: You read the --

22 MEMBER MOYER: I'm reading the survey

1 and reading the survey, it's almost the same. I
2 mean, did you and your provider talk --

3 CO-CHAIR SUSMAN: Yes.

4 MEMBER MOYER: -- did your provider
5 talk to you about refilling your own
6 prescriptions? How often did you schedule your
7 own appointments? Did your provider talk about
8 your health insurance? These are -- to me, these
9 are materially the same as the FECC questions
10 there. It's a patient experience of care, but
11 it's not a patient outcome. Do you see --

12 CO-CHAIR SUSMAN: I'm not arguing one
13 way or the other about what it should be, it just
14 seems that we would be treating this measure and
15 the FECC measure in a fundamentally different way
16 when, I think, they're the same exact concept.

17 MEMBER MOYER: But what are we --

18 MEMBER MILLER: And this is --

19 MEMBER MOYER: -- it to?

20 MEMBER MILLER: This is Marlene and I
21 will just chime in. I also agree, being a
22 reviewer, both primary reviewer on the FECC

1 measure and these, these strike me as the same,
2 and this little nuance here was lost on me
3 because they seemed identical as surveys of
4 processes of, did these various things happen?

5 MEMBER HOUTROW: And this could have
6 been, it could have been presented to us as a
7 measure of process, in which we looked in the
8 medical record to see if the physician documented
9 that he had a conversation about medication,
10 right?

11 And it's the same process that we're
12 looking for evidence of, whether you survey the
13 parent, or whether you survey the child, or you
14 survey the medical record.

15 But, my question comes back to, what
16 are we obligated to do with number one, if we're
17 being told this is a patient-reported outcome?

18 MEMBER JOHNSON: So if it is
19 considered a PRO, then the question for you is,
20 is there something that providers can do, at
21 least one thing that providers can do, to affect
22 the -- basically, the results that somebody would

1 report on the survey?

2 CO-CHAIR BROOKEY: David.

3 MEMBER KELLER: So it -- boy, this is
4 an interesting existential question, isn't it?

5 (Laughter.)

6 MEMBER KELLER: Because, I'd have to
7 agree that, you know, in the construct of the
8 triple aim, patient experience is an outcome.
9 And, yet, and so I think our confusion is not so
10 much, I get why this is being considered an
11 outcome, our confusion is, really, why was the
12 other not considered an outcome?

13 CO-CHAIR BROOKEY: Right.

14 MEMBER KELLER: Because, yes, they
15 were looking at processes. But, again, they were
16 looking at it from the patient's point of view,
17 which would have made it a patient experience,
18 rather. And I'm thinking, for consistency, we --
19 I'm now confused. Is it just -- is it why we
20 didn't pick up on this before?

21 I mean, and, you know, and it gives us
22 a little bit of reflection. I get why we -- but

1 I actually think we should treat this this way.

2 I guess, I'm thinking we made a mistake in not
3 treating the other one this -- that way, in the
4 same manner.

5 MEMBER HOUTROW: Those aims are better
6 health, which is the patient-reported outcome;
7 better experience, which is patient-reported; and
8 better efficiency of care, right, which is a
9 health systems issue. So you think -- right,
10 health care, yes.

11 DR. NISHIMI: Please. Mic, please.
12 Microphone, please.

13 MEMBER MORROW-GORTON: So just
14 thinking about it, wasn't the one we just talked
15 about based on chart review, not based on what
16 the patient, or family, said?

17 Or was it a survey? Okay.

18 CO-CHAIR SUSMAN: It's a series of
19 nested surveys.

20 MEMBER MORROW-GORTON: Okay.

21 CO-CHAIR SUSMAN: If that's the case,
22 I mean, I guess, one option is for us to review

1 what we did with FECC and use the same standard.
2 I don't think it's going to change, actually,
3 anything we decided about evidence, which is
4 pass, or no pass.

5 CO-CHAIR BROOKEY: Yes, I think so. I
6 would recommend that we go ahead and consider
7 this one to be a health patient-reported outcome
8 and take it though the top of the algorithm.

9 I think that we can huddle about the
10 others, but I think that it wouldn't be very
11 difficult to flip those into the same questions
12 and we've already had the discussion, so I don't
13 think it would take very long to go ahead and go
14 through those, tomorrow, while we're -- maybe, if
15 we finish early, today.

16 So that would be one recommendation.
17 But I think, maybe, we should go ahead and
18 consider this one to be a patient-reported
19 outcome. So we have a bunch of people here, so,
20 Kevin, why don't you go ahead and start.

21 MEMBER SLAVIN: Yes. I think --

22 CO-CHAIR BROOKEY: There you go.

1 MEMBER SLAVIN: Sorry. Guess I
2 shouldn't hold it. I think if we were to flip
3 the FECC measures into this same patient-reported
4 outcome, they would have to be taken en bloc,
5 rather than as individual pieces.

6 Because we're no longer so concerned
7 about the individual evidence and whatever and it
8 would have to be, sort of, looked at the same way
9 that this is.

10 CO-CHAIR BROOKEY: Let me just comment
11 that the discussion we just had is still relevant
12 and important for future tweaking of those
13 measures, so we would take that into
14 consideration, whether we would just go ahead and
15 vote them all, as ten, ten at once. So good
16 point.

17 MEMBER FEI: The other thing, for the
18 FECC measures, since they were submitted as
19 process measures, we'd have to get the
20 developer's agreement that they would want them
21 considered as patient-reported outcome measures,
22 as well.

1 CO-CHAIR BROOKEY: Okay.

2 MEMBER QUINONEZ: Yes, I think there's
3 no absolute objective way to handle the question
4 that we're arguing right now, and so I would
5 agree with the fact that we should consider this
6 one a patient-reported outcome, but we should
7 leave the other one as it stood. Because, it was
8 a robust conversation, and I think, you know, we
9 voted based on that robust conversation.

10 CO-CHAIR BROOKEY: Okay, we're going
11 to take all these comments into consideration.
12 So thank you. Who else has their hand up here?
13 Jeff.

14 MEMBER SCHIFF: I have to make up for
15 lost time. I wanted to -- I had, I wanted to ask
16 you for the NQF staff, if there's a difference in
17 the quality of the endorsement coming in as a
18 patient-reported outcome versus a process
19 measure? I'm getting a no. Okay.

20 MEMBER JOHNSON: For the record, there
21 is not.

22 MEMBER SCHIFF: Okay. And then, I

1 just want to be -- I just, this is to David's
2 existential comment about this. I think we have
3 to be clear that there's a lot of
4 patient-reported things that are process, but
5 because they're reported in document and the
6 medical record, they become a process measure of
7 care, be it a depression screen or anything like
8 that. If it's -- it seems like what we're really
9 talking about is whether the collection mechanism
10 occurs outside of the office to assess the
11 quality of the care in the office, or the
12 patient's outcome.

13 CO-CHAIR BROOKEY: Carol.

14 MEMBER STANLEY: So I'm a little
15 confused. With this particular measure, it seems
16 like some of it's patient experience and some of
17 it is outcome. Because you ask about if the
18 physician talked about your prescription drug
19 use. But then there's another question that asks
20 or about making your own appointments. And then
21 it asks, specifically, your behavior, have you
22 scheduled your own appointment.

1 So one of those is an indicator,
2 because the behavior has -- there's an actionable
3 behavior, which is an outcome, versus the process
4 measure is, were you counseled about making your
5 own appointment?

6 I also have concerns about the age
7 group that's targeted for this survey, age 16 to
8 17. Is it realistic for a 16-year-old to call
9 and make their own appointment and to -- and call
10 and get their prescriptions refilled? So that's
11 part of the questions that we're talking about
12 and --

13 CO-CHAIR BROOKEY: Right. Karen.

14 MEMBER DORSEY: I just want to, you
15 know -- it just occurred to me, just hearing the
16 conversation, that this is a little bit different
17 from the FECC, because -- I mean, one way to
18 think about it is that the transition from
19 pediatric to adult care is inevitable, right.
20 It's an inevitable part of the structure of our
21 health care system.

22 And so I think you can reasonably

1 think about -- whether they be processes or
2 behaviors around that transition, as being
3 patient experience, because it's an experience
4 they're going to have, one way or the other.

5 Whereas, care transitions, we'd have
6 to sort of make an analogist argument, perhaps,
7 right? And say, suggest every child with complex
8 medical conditions requires the level of care
9 transitions as -- I mean, care coordination
10 that's described.

11 We may all agree to that, right, but
12 it's a little bit qualitatively different to me,
13 because, you know, pediatric to adult transition
14 is inevitable. Nobody's in control of that.
15 That's going to happen. And so this can be
16 thought of, even if it describes processes, as an
17 experience of that transition, no matter what.

18 CO-CHAIR BROOKEY: So we can take a
19 couple more comments and then we're going to ask
20 for a decision about voting for this, based on
21 the top box.

22 I think what we're going to do, first

1 of all, we're going to go back to the FECC
2 measures, we're not going to lose any of the
3 conversation that we had, or any of the voting
4 that we've made that will actually help the
5 developers go back and look at the measures.

6 So everything that we did has been
7 captured and will go back to the developers for
8 future discussion. But, I believe we will go
9 ahead and vote on them tomorrow, yes/no,
10 according to the top box.

11 But, I think our conversation will
12 help inform that vote. So I'd like to get the
13 approval to move forward with voting yes, or no,
14 on this particular measure. But are there any
15 other comments, before we move in that direction?
16 So, David.

17 CO-CHAIR BROOKEY: Carol.

18 DR. SAWICKI: Just a few points to
19 respond to some of the comments that have been
20 made. I think the comment that pediatric to
21 adult transition is inevitable is, certainly, an
22 appropriate and valid one. But, the literature

1 does tell us that there's a lot of deficiencies
2 in how it happens and it's very haphazard. And I
3 think that we would be remiss to not have some
4 role for providers and health care systems to try
5 to make it better. And it doesn't have to be,
6 you know, the same level of care for everybody,
7 but I think that ignoring that and just saying
8 it's inevitable is, probably, missing the point.

9 And the comment around the role of
10 providers, I think that, to the point that a
11 provider could actually impact change, we spend a
12 lot of time in developing this. So about specific
13 wording, were we asking the adolescents to report
14 on what their provider did, or whether it was
15 somebody else in the office, we had a lot of
16 comments that said, it's the social worker, the
17 care coordinator, the nurse.

18 And, fundamentally, we agree that
19 there are lots of different ways that transition
20 care can be planned. But if the physician and
21 provider is not part of that discussion, is not
22 initiating or having these discussions, these

1 kind of programs are, probably, going to fall
2 apart.

3 So even though we don't expect the
4 provider to be doing everything, we do expect
5 them to be having conversations. And so from an
6 accountability perspective, we really did feel
7 that it was important to ask about what the
8 provider was doing.

9 And then, some of the things here
10 about the age range, the measure simply asks
11 whether you received some counseling. And there
12 are some questions about whether you are doing
13 certain actions, and there are some teenagers who
14 are doing some of these things.

15 It's not an expectation of the measure
16 or the measure score, but we didn't want to
17 penalize someone, from a score perspective, if
18 they had a teenager, or a teenage population that
19 was doing really well and were filling their own
20 prescriptions. For instance, for birth control
21 for an adolescent female, they are responsible
22 for doing that, in many situations.

1 We didn't want them to get a lower
2 score, because they were told that they're not
3 talking about it. Because they maybe mentioned
4 this when someone was 15 and was asking for birth
5 control.

6 So that was sort of part of routine
7 adolescent care, and so the age range that was
8 chosen didn't go as low down as the AAP, which
9 says 14, and some consensus guidelines down to
10 age 12, but we felt that, by age 16, some of
11 these conversations should have been started.

12 CO-CHAIR BROOKEY: Just another
13 question, before we vote. We have a couple more
14 comments. Is there any consideration to
15 adjusting the age range? Was that discussed, or
16 is that sort of a final decision, based on
17 consensus?

18 DR. SAWICKI: I think we talked about
19 the appropriate age range. We felt that going
20 below 16 would be inappropriate, from an
21 adolescent-reported measure.

22 But we have, certainly, talked to

1 certain health systems, and there are, certainly,
2 18, 19, 20-year-olds -- these questions apply to
3 a 25-year-old as well, and so I think there could
4 be some discussion around increasing the age.

5 CO-CHAIR BROOKEY: Jenny.

6 MEMBER MOYER: Yes, my only question
7 is that, I request that it be very clear what it
8 is we're voting on, because I'm having difficulty
9 reading the box, knowing how to interpret that.

10 MEMBER HOUTROW: That was my question,
11 as well. So if I were to read this, I would say,
12 rationale supports the relationship of the
13 teenager reporting receipt of transition
14 counseling to at least one health care structure
15 process intervention or service, in this case,
16 the process of a physician delivering counseling.
17 Is that right?

18 CO-CHAIR BROOKEY: The green box says
19 -- if I take out the extraneous words and just
20 put in the PRO piece of it, it says, does the
21 measure assess performance, from a PRO, because
22 it's an or PRO, so it's -- whatever it's looking

1 at, it's just a PRO, and is that what we're
2 assessing performance on? But that's not what
3 the words on the screen are. Just look at the
4 green -- do they all have this?

5 MEMBER HOUTROW: It seems a little bit
6 circular, right? So the PRO is the patient's
7 report of receipt of services, which is related
8 to the process of physicians providing those
9 services.

10 CO-CHAIR BROOKEY: But it's still a
11 perception of the patient, because it's a
12 patient-reported outcome, so it's not a
13 definitive process measure where we go into the
14 chart and see if they actually documented it,
15 it's a patient's experience. So which may differ
16 from what the chart would reflect, so that's why
17 it's different.

18 MEMBER MOYER: But this is not a
19 health outcome. And the first question is, is it
20 a health outcome, or mortality --

21 CO-CHAIR BROOKEY: Or, or --

22 (Simultaneous speaking.)

1 CO-CHAIR BROOKEY: -- or a PRO.

2 Yes, so strike out outcome, we're
3 looking -- it's just a PRO. Does this assess
4 performance, based on patient's reported outcome?
5 You have to look at the green box and not the
6 screen up there.

7 MEMBER MOYER: And it's -- okay. And
8 you're interpreting experience to mean the
9 patient's experience of care, not the patient's
10 experience of his health?

11 CO-CHAIR BROOKEY: Right.

12 MEMBER MOYER: Okay. I interpreted
13 that as the patient's experience of his health.
14 Okay, so patient's --

15 CO-CHAIR BROOKEY: Right. I would
16 agree that that green box does not reconcile with
17 that white screen. So we're voting on, does the
18 measure assess performance from a
19 patient-reported outcome survey, period.

20 MEMBER QUINONEZ: So, I -- and this
21 might be just because I'm new at this, but I feel
22 really uncomfortable voting on this top green

1 part, because it feels almost like that is way
2 too low of a bar to set for an outcome, for a
3 measure.

4 It basically ignores the evidence.
5 And if you can prove that what you're trying to
6 measure is measured by what you're trying to do,
7 you pass. I mean, you could, basically, have no
8 evidence for a measure and still pass.

9 CO-CHAIR BROOKEY: Right. So look at
10 the white screen again. So the rationale
11 supports that this measure assesses performance
12 from a PRO. I think we need to change that
13 question, otherwise, it's quite confusing.

14 So the rationale is all this
15 discussion around the evidence, or lack of
16 evidence, so you have to believe that it's strong
17 enough to support a yes or a no -- a yes response
18 on this. Yes.

19 DR. BURSTIN: Just a little bit of
20 context. It's a good question, regard when it
21 comes up all the time. And I'll say, when we had
22 our evidence task force, I don't know, five, six

1 years ago, one of the key questions was, is the
2 evidence requirement the same for an outcome
3 measure versus a process instructional measure?

4 And the ultimate decision was that you
5 could move an outcome measure forward, even if
6 you didn't yet know the evidence-based processes
7 that it's linked to, because sometimes having the
8 outcome measure out there first drives the work
9 to figure out the processes.

10 And the classic example is central-
11 line associated bloodstream infection where, you
12 know, that outcome measure was out, reported, and
13 then the processes began to emerge.

14 I think there was a lot of concern of
15 not holding back outcome measures that are
16 otherwise important, while waiting for the --

17 MEMBER QUINONEZ: Except that it --

18 DR. BURSTIN: -- development of
19 processes, yes.

20 MEMBER QUINONEZ: Except that example
21 had a lot of --

22 DR. BURSTIN: Yes.

1 MEMBER QUINONEZ: -- evidence basis
2 behind it.

3
4 You know, there was a lot of evidence
5 that checklist helped and that --

6 DR. BURSTIN: Not at the time the
7 measure was endorsed. Not initially.

8 MEMBER MOYER: The argument I would
9 make is not that, because I completely agree with
10 that. It's that what this outcome is -- this
11 patient-reported outcome, is the patient
12 reporting whether a process occurred, so it's a
13 measure of whether a process occurred.

14 DR. BURSTIN: All of our PRO work to
15 date, we have included patient experience within
16 that bucket of PROs, which, I think, is what's
17 confusing.

18 Most patient experience measures do
19 report on, did you get the information in a way
20 you can handle it, did you get -- they're often
21 did you get, dot, dot, dot, so it's not that far
22 off.

1 In Europe, for example, they'll
2 separate PRO measures from PREMs,
3 Patient-Reported Experience Measures. We've, at
4 least -- the work we've done determined that they
5 should be held to the same standard, but it's a
6 fair question.

7 CO-CHAIR BROOKEY: I think what the
8 Committee is struggling with is that there's a
9 huge gap between voting for the evidence, or
10 voting just for this rationale. And, it seems
11 like we're holding this particular one to a
12 different standard, which is why we talked about
13 revisiting those earlier measures, tomorrow.

14 So I guess, the response would be that
15 you have to listen to the rationale, what
16 evidence there is or is not to support moving
17 this forward, before voting yes on this. And
18 it's just a completely different way of thinking
19 about this measure.

20 There is no evidence. Insufficient
21 evidence. We stated that this would go -- if
22 this were to go for, down the linear -- the

1 vertical path, it would go down to whether or not
2 this is limited, or insufficient evidence with
3 exception.

4 DR. SAWICKI: The specific question
5 that's being asked is -- and I think was raised
6 with the first comment was, is there evidence to
7 connect what a physician counsels an adolescent
8 and an outcome. So that's one.

9 That's a specific question. There's
10 plenty of evidence that says that physicians and
11 care teams and health systems are doing a
12 disservice to adolescents with chronic health
13 conditions in not preparing them for adult care.

14 So I think, from a level of evidence
15 perspective, this is an important topic to
16 capture in a patient experience measure. That is
17 -- that's the argument that our team will make.

18 This is, also, a novel measure in that
19 it is actually asking the adolescent, so we're
20 pediatricians, you know, a lot of us in the room,
21 and a lot of the measures on transition that have
22 been used by MCHB, by other organizations, have

1 been parent-reported measures and proxy measures.

2 And there is a place for proxy
3 measures, particularly in children and young
4 adults with cognitive delay and disabilities and
5 things that they couldn't report on their own
6 processes of care.

7 But there is a rationale to think
8 about how adolescents are reporting on their
9 care, and there is an evidence base to suggest
10 that there is sub-optimal care being provided to
11 adolescents.

12 CO-CHAIR BROOKEY: Just one more
13 comment. And, at least in Kaiser, in
14 California, our attorneys will not allow us to
15 survey 16-year-olds. So we, can we -- there's
16 this period between 12 and 18 that they're -- we
17 cannot survey them. So --

18 DR. SAWICKI: In our field test, we
19 worked with two Medicaid plans in Texas and in
20 Pennsylvania and neither have that concern.

21 CO-CHAIR BROOKEY: It may be state-by-
22 state, depending on their interpretation, I don't

1 know.

2 DR. SAWICKI: The mailing was directly
3 to the parent, not to the adolescent, so we
4 weren't allowed to mail directly to the
5 adolescents.

6 CO-CHAIR BROOKEY: Okay. Any other
7 questions, comments? Amy.

8 MEMBER HOUTROW: I just want to go
9 back to the clarification of what outcome we're
10 talking about and what process we're talking
11 about. So the process of interest that underlies
12 the outcome is that the physician did something
13 to talk to the patient about transition. And the
14 outcome is the report that the patient was talked
15 to about transition. Not that they were ready
16 for transition, or it changed their readiness,
17 right? It's about, whether they just reported
18 that that thing happened, as the outcome, which
19 you have to then say that they are linked,
20 because there's a clear relationship. If you do
21 something, as a physician, and the patient
22 reports that you did it, there's obviously a

1 link. If you didn't do it and they report that
2 you didn't do it, then there's obviously a link.
3 But that puts us out of talking about any of the
4 kind of evidence that you were just speaking
5 about, which there is a wealth of evidence that
6 we're not doing well transitioning kids.

7
8 ***PART 4 Section B*** 4:22:03

9 CO-CHAIR BROOKEY: All right. So
10 we're still talking a patient-reported outcome
11 survey. So we're going to take it through the
12 green track. And the question, and I'll let you
13 go, David, but the question we're going to ask
14 is, whether or not you feel that the rationale
15 supports this particular PRO in, basically,
16 assessing performance? David.

17 MEMBER KELLER: This is, actually, a
18 comment from a while ago. Just back to the age.
19 I would argue that the age that was selected by
20 the measure developers was actually the perfect
21 age to do this.

22 And I'm very, because what you are

1 trying to do is capture this before the children
2 turn 18, is because what we're really trying to
3 do is measure readiness for the transition and
4 the transition happens at 18, the common one
5 being around mental health and mental health
6 medications.

7 And if you haven't prepped for that,
8 at age 18, all of a sudden they get, just, all
9 sorts of bad things happen. So I'd applaud that
10 measure. I just wanted to put that out there, as
11 a thought on the age criterion.

12 CO-CHAIR BROOKEY: Do people feel like
13 they have enough information to vote, whether
14 they support the rational? Hold on for just one
15 second. Does the Committee feel like they have
16 enough information to vote?

17 So I'm going to ask the question,
18 you're going to tell me whether I got it right,
19 okay? We're voting on this patient-reported
20 outcome survey, as to whether or not the
21 rationale, provided by the developers, supports
22 the fact that this measures, that this survey

1 assesses performance on a patient-reported
2 outcome survey. And I'm just putting all the
3 words together, because it's not on one screen.
4 Is that clear?

5 (Off microphone comment.)

6 CO-CHAIR BROOKEY: Well, let's talk
7 about what's a factor. It is a patient-reported
8 outcome survey, right? So according to the
9 algorithm, it would go in the green pathway. And
10 then, even though the green pathway doesn't state
11 it, the question on the white screen is, we're
12 really supporting the rationale that is
13 supporting this survey. So based on everything
14 you've heard, whether there's evidence, indirect
15 evidence, or direct evidence, is the rationale
16 sufficient to support this survey? That's what
17 we're voting yes, or no.

18 (Off microphone comment.)

19 CO-CHAIR BROOKEY: Can you use your
20 mic?

21 MEMBER MOYER: I think Amy and I are
22 struggling with the same thing. That, if the

1 question wants to know, if there's a relationship
2 between the patient-reported outcome, which is,
3 did your doctor do this, and the process, which
4 is, did your doctor do this? Well, there's the
5 relationship between those two things,
6 theoretically, is one to one, either your doctor
7 did it, or your doctor didn't. Now the patient
8 may not report that it was done. We've all had
9 the experience of having people report that you
10 didn't do something. Your spouse is pretty sure
11 that you didn't do something that you're pretty
12 sure you did do. But, so I mean, we all know
13 that that can happen, but the health outcome that
14 it's, the patient-reported outcome is whether
15 counseling occurred and the process is
16 counseling, so there's a one-to-one relationship
17 between those two things, there's no need for a
18 rationale.

19 MEMBER HOUTROW: There's no need for
20 evidence.

21 MEMBER MOYER: Or evidence.

22 CO-CHAIR BROOKEY: Right. So that's

1 the second box, we're just, we're on the first
2 box.

3 MEMBER HOUTROW: We're on the second
4 box, though.

5 CO-CHAIR BROOKEY: But I'm on the
6 first box.

7 (Laughter.)

8 CO-CHAIR BROOKEY: So we have to get
9 out of the first box to get to the second box.

10 MEMBER MOYER: But you said that this
11 was a patient, I mean, and Helen confirmed that
12 this --

13 CO-CHAIR BROOKEY: Yes.

14 MEMBER MOYER: -- we've answered the
15 first box, there's no question about that.

16 MEMBER HOUTROW: So the first question
17 is yes, we accepted that this experience is a
18 patient-reported outcome.

19 CO-CHAIR BROOKEY: But, do we need to
20 vote on the first box, because that's, that's
21 what's on the screen right now? Why don't we
22 vote on the first box, because we -- all right,

1 so we're going to assume it's a PRO, so we're
2 going to go to the second box now. So now we're
3 voting on, and again, the words are not on the
4 screen, right?

5 So the second box says, does the
6 Committee agree that the relationship between the
7 patient-reported outcome survey and, at least,
8 one health care action structure process,
9 intervention, or service, is identified and
10 supported by the stated rationale?

11 CO-CHAIR SUSMAN: Isn't part of this
12 that the denominator population values this
13 patient-reported outcome, isn't that, really, the
14 question we're trying to answer here?

15 And I think there's some good
16 evidence, or at least, a suggestion that they do
17 value this information, as they've reported. And
18 that, to me, clarifies the question a little bit
19 that we're trying to vote on, at this point. Or
20 not.

21 CO-CHAIR BROOKEY: Go ahead, Jeff.

22 MEMBER SCHIFF: I, while I agree with

1 Jenny and Amy, I think the issue here is about
2 how the data's collected. Because when we looked
3 at the FECC, we were talking about the novel way
4 in which we were collecting information on these
5 processes of care.

6 And I think that, to me, I'm not sure
7 if it's on the screen correctly, but I think what
8 we're really saying is, to me, it's, does the
9 novel way of asking the adolescents, in that time
10 frame, about whether or not they got that care,
11 warrants a pass/fail on a patient-reported
12 outcome, because of the way the data's being
13 collected.

14 You could get the same data documented
15 in the record, but that's not what we're actually
16 measuring. What we're trying to measure, I
17 think, is whether or not the patient felt they
18 received it.

19 CO-CHAIR BROOKEY: Right. So going
20 back to the question. It's a survey. We know
21 it's a survey. We know what it's measuring. And
22 does it, is it related to, at least, one health

1 care action, as stated in the rationale? So
2 medication management would be just one aspect of
3 it.

4 CO-CHAIR SUSMAN: Or alternatively, is
5 it related to outcomes, or processes that the
6 adolescents, themselves, value? I mean, is that
7 experience of import to them?

8 CO-CHAIR BROOKEY: Anymore clarifying
9 questions for the developers?

10 (No audible response.)

11 CO-CHAIR BROOKEY: Any objection to
12 voting?

13 (Pause.)

14 CO-CHAIR BROOKEY: You're objecting,
15 Ricardo?

16 MEMBER QUINONEZ: Yes.

17 CO-CHAIR BROOKEY: Karen.

18 MEMBER DORSEY: So I don't, I'm
19 feeling like we're complicating things, a little
20 bit, because it seems to me that what the second
21 box is asking is, can the, sort of, intended
22 target in the health care system have an impact

1 on the patient's experience?

2 Is there, can we imagine that,
3 something the health care provider does, can
4 impact the patient experience? That seems like a
5 pretty low bar. That seems like a pretty clear
6 yes. But it's a, to me, it's a separate question
7 to say, is this a valuable measure?

8 I mean, is it contributing something
9 valuable, such that we think it's appropriate for
10 endorsement, and I don't think that's the
11 question we're trying to answer with this first
12 vote.

13 I don't know where that comes, downs
14 the line, maybe it comes when we talk about
15 validity, or use and usability, but it seems, to
16 me, that this is a very straightforward question
17 to say, do health care providers have some
18 ability to impact this patient experience? And
19 that seems like a pretty clear yes, to me.

20 And then, at some point, we're going
21 to talk about, whether this is a valuable
22 contribution to this particular area of medicine

1 of transitions.

2 CO-CHAIR BROOKEY: Ricardo.

3 MEMBER QUINONEZ: So the, the thing
4 that makes me the most uncomfortable is that,
5 we're supposed to be voting on the evidence, for
6 this part of the -- and that algorithm ignores
7 the evidence.

8 I would feel much more comfortable,
9 and I, kind of, agree that it's a, I'm try, I've
10 been trying to imagine ways in which you could
11 answer yes, and the answer to number two be no,
12 and it's very hard for me to find it.

13 And so I would be much more
14 comfortable, if we voted on the green algorithm,
15 but we separately voted on the strength of the
16 evidence, you know, and whether that, you know
17 what I mean? That, that would be, to me, that
18 would, that would make a lot more sense, when
19 you're assessing --

20 DR. BURSTIN: I have plenty more
21 examples of --

22 MEMBER QUINONEZ: -- quality of

1 evidence.

2 DR. BURSTIN: -- outpatient rationale,
3 by the way.

4 (Simultaneous speaking.)

5 DR. BURSTIN: There are numerous
6 outcomes that go down in rationale, because there
7 are no clearly processes, or anything related to
8 them, where committees have been very
9 uncomfortable putting an outcome forward, without
10 even a rationale.

11 So it, you know, again, this is an
12 issue we've had, lots of, you know, some members
13 get uncomfortable about this. I think it's very
14 much the sense of trying to not hold outcomes
15 hostage, until you've got, so the processes
16 instructors in place around them, is the logic of
17 it. But I understand where you're coming from.

18 CO-CHAIR BROOKEY: So my
19 recommendation is that we move it forward to a
20 vote, and we have very clear comments that we're
21 going to document about the concerns, not only
22 about the process, but as well as, the fact that

1 this process does not allow us to, sort of, vote
2 on the evidence, the strength of the evidence, or
3 even to have an option for insufficient evidence
4 with an exception.

5 Because I don't think that we're all
6 going to all feel comfortable with this, in any
7 other way. Does that make sense? I mean, it's,
8 it's, I think we need to move on to the next
9 aspects of this measure, which, I think, will be,
10 probably, an easier conversation. So any
11 objection to moving forward with voting?

12 (No audible response.)

13 CO-CHAIR BROOKEY: Okay, let's go
14 ahead and vote.

15 MS. CHAVEZ: Okay, we're voting on
16 Measure 2789, Adolescent Assessment of
17 Preparation for a Transition to Adult-focused
18 Health Care.

19 Does the rationale support the
20 relationship of the PRO, to, at least, one health
21 care structure, process, intervention, or
22 service, yes, or no? One for yes, two for no.

1 Voting's open.

2 (Pause.)

3 MS. CHAVEZ: We are expecting 24
4 votes. There is one recusal. Seventeen, 18, 22,
5 24. Twenty-two voted yes, two voted no. The
6 measure passes evidence.

7 CO-CHAIR BROOKEY: So let's move on to
8 performance gap, and I'm going to ask Marlene,
9 Amy, or Kerri, to comment.

10 MEMBER MILLER: This is Marlene. I
11 heard everything. I don't supervise PRO, but I, I
12 thought there were certain minimal data on a
13 performance given compared to adolescents who,
14 you know, comparing, you know, their transition
15 score, you know, how he did on it versus teens
16 that weren't well-prepared.

17 I couldn't really understand if the
18 survey, actually, therefore, detects transition
19 readiness. You want some control, not to say
20 that kids that aren't well-prepared, this is how
21 they scored, versus kids that are well-prepared,
22 this is how they scored, but I didn't see

1 anything like that, so I have, I really couldn't
2 comment, as to whether there is a gap, in a sense
3 that this measure can actually address it.

4 CO-CHAIR BROOKEY: Amy, or Kerri.

5 MEMBER FEI: I don't know that there's
6 anything, actually, from the survey that would
7 help us with gap. If you guys want to chime in
8 on what you found? There was a little provided
9 in the documentation, but I'm not sure that it
10 demonstrates, numerically, that there's a huge
11 gap.

12 DR. SAWICKI: Well, the goal of our
13 field testing was to quantify, at a health plan
14 level, or at a hospital level, the performance on
15 these three scores. It was not, we did not use
16 multiple, or other, instruments to then
17 differentiate whether youth were prepared, or had
18 readiness on other measures.

19 There's, certainly, other measures
20 that can evaluate transition readiness, in other
21 ways, but the data that we got, uniformly, across
22 the three sites show that there was a gap in

1 performance, meaning that the scores were quite
2 low in all three, particularly, for the
3 transition planning domain where less than ten
4 percent, on average, of any of the youth stated
5 that they even had a discussion about
6 transferring care.

7 In terms of the, the highest scores
8 were in the medication, prescription medication
9 domain, about 60 percent on average. And in the
10 middle, with on the transition self-management.
11 And we looked at it, the individual item, at the
12 composite level.

13 And, you know, from a perspective of
14 someone who thinks about adolescent medicine, the
15 one question in the transition self-management
16 domain is, did your provider meet with you,
17 without your parent in the room, and only 30
18 percent, across the board, said yes.

19 So I think all, if you're looking at
20 the of a, is there a performance gap? We didn't
21 look at differences, based on different
22 populations, in that way, but we identified that

1 there is a gap, at a population level.

2 CO-CHAIR BROOKEY: Other questions,
3 comments, about performance gap? Ricardo.

4 (Off microphone comment.)

5 CO-CHAIR BROOKEY: Okay. Oh, you got
6 your voter? Okay, you're ready to vote? All
7 right, we'll vote.

8 MS. CHAVEZ: Okay. We're now ready to
9 vote on gap for Measure 2789. Options are one
10 for high, two moderate, three low, four
11 insufficient, and voting's open.

12 (Pause.)

13 MS. CHAVEZ: Eighteen. Twenty-two.
14 Twenty-three, 24. Two voted high, 16 voted
15 moderate, five voted low, one voted insufficient.
16 This measure passes gap.

17 CO-CHAIR BROOKEY: So let's move on to
18 reliability. And I'm not sure who's going to tee
19 up the conversation about reliability.

20 MEMBER MILLER: This is Marlene. I'll
21 just, I'll say that on my sense of reliability, I
22 didn't really so many kinds of things, like

1 repeated testing with same population, the
2 testing that was done was three, sort of,
3 geographically disbursed areas.

4 But, I don't have, I couldn't see any
5 information on how similar these populations,
6 test populations, in these areas were, because
7 they were, literally, just spread across the
8 country, so I, I didn't think their, their
9 reliability was very hard to determine.

10 CO-CHAIR BROOKEY: Developers want to
11 comment?

12 DR. SAWICKI: So I think there are
13 several ways to think about reliability for a
14 survey measure. One that we did do was look at
15 the interim reliability when developing the
16 composites and that did show quite strong ordinal
17 alphas, from a perspective of, do the questions
18 hold together, as a construct?

19 And so that's one measure of
20 reliability for a survey instrument that I think
21 was done, in terms of the populations,
22 themselves, two were for Medicaid health plans,

1 they were geographically disbursed.

2 So they were, somewhat, different, in
3 terms of race and ethnicity, but we were limited
4 in the amount of data that we had from claims to,
5 to do much more, in terms of looking at very many
6 differences.

7 We didn't have the numbers, really, to
8 be powered to look at race, ethnicity
9 differences, for instance, as an example. But
10 from a survey development perspective, our
11 contingent is, that the reliability is there from
12 a, from a statistical perspective.

13 MS. MUNTHALI: Sorry, we were just
14 discussing the number of items that might be in
15 this measure, so perhaps you can elaborate, a
16 little more, on that? We just want to make sure
17 that, in terms of process, we're following the
18 same process, as we did with the fact, which had
19 multiple items in a measure.

20 DR. SAWICKI: So the survey, itself,
21 consists of 26 questions, not all of them are
22 used in development of the score. And then, for

1 each of the three domain scores, there are either
2 four or five items that fall within each of the
3 domain scores.

4 MEMBER JOHNSON: So do you consider
5 each of the domains a separate performance
6 measure?

7 DR. SAWICKI: So they each encompass a
8 different aspect of care around transition
9 counseling. Each individual item I do not
10 consider, as a separate measure, as many of them
11 are intimately linked and our factor analysis
12 that we did, also show that there was a good link
13 between the composite questions.

14 They do have three different
15 constructs that they capture, when it comes to
16 thinking about, sort of, validity and face
17 validity of what these different constructs are.
18 They are, somewhat, separate, albeit,
19 potentially, related, in a global sense.

20 CO-CHAIR SUSMAN: So when you finally
21 end up scoring this, is it scored as one
22 composite score for all three domains?

1 DR. SAWICKI: It's one, one score for
2 each domain, separately.

3 CO-CHAIR SUSMAN: Okay, so --

4 DR. SAWICKI: But the survey --

5 CO-CHAIR SUSMAN: -- there will be
6 three scores?

7 DR. SAWICKI: -- was administered, as
8 a -- that would be three scores.

9 CO-CHAIR SUSMAN: Okay. Thank you.

10 MEMBER JOHNSON: So if it's three
11 scores that's what we would consider three
12 separate performance measures. So like the FECC
13 that had ten different things in it, we're seeing
14 this one, as having three different things in it.

15 CO-CHAIR SUSMAN: Do you have the
16 information on reliability and validity, for each
17 of those domains, then? I know you have --

18 DR. SAWICKI: For the first two
19 domains we do have, well, we have reliability
20 data on all three domains, in terms of the
21 ordinal alpha, in terms of the factor analysis,
22 we were able to do a factor analysis on the first

1 domains, the third domain of transition planning,
2 the numbers were insufficient, by nature of the
3 responses.

4 So the actual question that the domain
5 refers to is, did you and this provider talk
6 about whether you may need to change to a new
7 provider, who treats, mostly, adults, and if
8 someone answered no to that, they skipped out of
9 the remainder of the questions, because if they
10 didn't have that first conversation, they can't
11 comment on anything else. And so that was, by
12 nature, a score of zero.

13 And so less than 15 percent in each of
14 the field test samples answered yes to that
15 question, so the numbers were insufficient to do
16 true validity testing for that particular domain.

17 CO-CHAIR BROOKEY: In terms, going
18 backwards to performance gaps, would there be any
19 difference between the three domains?

20 DR. SAWICKI: I think the gap is
21 present for all three.

22 CO-CHAIR BROOKEY: So I'm asking the

1 Committee, whether we need to go back and
2 re-vote, or can we just have one vote for all
3 three domains?

4 CO-CHAIR SUSMAN: I'm okay with the
5 one.

6 CO-CHAIR BROOKEY: Any objection to
7 leaving the vote, as is, for all three?

8 (No audible response.)

9 CO-CHAIR BROOKEY: Okay. It sounds
10 like, for the reliability, and I'm going to have
11 Carol make a comment, reliability, we may need to
12 vote for three different domains. So, Carol,
13 comment.

14 MEMBER STANLEY: Yes, getting back to
15 the question about age and the scoring that
16 you're talking about, as a composite. So am I
17 understanding correctly that, if one of the
18 respondents says that they were counseled about
19 prescription use, and also responded that they
20 haven't made their own doctor's office visit,
21 scheduled it themselves, in the past year, won't
22 that reflect poorly in the scoring?

1 DR. SAWICKI: The questions you cited
2 were, there's a scheduling of appointments, which
3 is not in the same domain, as the prescription
4 medicines, so in terms of the ones around
5 scheduling appointments, the way that we handle
6 it, in terms of the score, was that if someone
7 said that they had scheduled their appointments,
8 they got credit, full credit for that part of the
9 score, those two questions.

10 So the first question is, did you and
11 your provider talk about you scheduling your own
12 appointments, instead of your parents? If you
13 said no to that, but said that in the last 12
14 months you did schedule your appointments, you
15 still got credit, as a, as a, you didn't get
16 penalized for that.

17 MEMBER STANLEY: But what if they
18 talked about scheduling their own appointment,
19 but because of --

20 DR. SAWICKI: But they never did it,
21 correct.

22 MEMBER STANLEY: Because they're 16

1 years old, they --

2 DR. SAWICKI: So they still got credit
3 for that, because the conversation was had and
4 the counseling was recorded.

5 MEMBER STANLEY: Oh okay. Okay. All
6 right, got it. Thanks.

7 CO-CHAIR BROOKEY: So just to clarify,
8 the three domains are on the screen. The first
9 of which is counseling on transition
10 self-management, number two is counseling on
11 prescription medication, and number three is
12 transition planning. Number three is the one
13 that didn't have sufficient reliability testing?

14 DR. SAWICKI: It did not have
15 sufficient validity testing, I would --it has --

16 CO-CHAIR BROOKEY: Oh yes, I know
17 enough to --

18 DR. SAWICKI: It has face validity
19 testing, for sure, in terms of our focus groups
20 and cognitive interviews, as well as, sort of,
21 expert consensus. But it was unable to go
22 through the factor analysis, in terms of validity

1 testing.

2 CO-CHAIR BROOKEY: Okay.

3 DR. SAWICKI: In terms of reliability,
4 there was enough numbers to create the ordinal
5 alpha, coefficient for all three domains.

6 CO-CHAIR BROOKEY: For all three,
7 okay. Any further questions from the Committee,
8 before we vote? Go ahead.

9 MEMBER THACKERAY: You had touched,
10 briefly, earlier, on the idea that this had to be
11 the health care provider, the physician, or nurse
12 practitioner, can you expand on that, a little
13 bit, why it has to be that specific individual,
14 and I guess, not having gone through the studies
15 that are referenced, do the studies also support
16 that it needs to be the physician, or is there
17 recommendations, or evidence to support use of a
18 social worker, use of a care coordinator?

19 DR. SAWICKI: The consensus
20 guidelines, certainly, do state that care
21 coordinators and other ancillary staff can be
22 involved in transition planning.

1 As part of our validity testing, we
2 did do focus groups with young adults, parents,
3 and teenagers, and all of those situations, it
4 was very clear that, despite what we may think,
5 as health care practitioners, the youth really
6 identify their doctor, as their provider, as
7 their main point of contact to the health system,
8 if they, in fact, had a doctor that they went to.

9 And so we really felt strongly that,
10 from this perspective of measuring an experience,
11 we wanted to make sure that they were anchoring
12 it to their provider.

13 DR. SCHUSTER: Yes, I'm going to just
14 add to that. That, the survey, in no way,
15 suggests that you wouldn't, in a practice, have a
16 social worker, case manager, or someone else help
17 with a lot of this.

18 But the idea is, this is a major
19 transition, one of the scariest parts of these
20 kids' lives, and they want and the profession is
21 saying that it's the primary provider, who has to
22 introduce the topic, or at least discuss it.

1 That the message has to come from the provider
2 and not just others, but others can still play a
3 role.

4 CO-CHAIR BROOKEY: Jeff.

5 CO-CHAIR SUSMAN: Vote.

6 CO-CHAIR BROOKEY: Jeff wants to vote.

7 All right?

8 (Laughter.)

9 CO-CHAIR BROOKEY: Okay. So we're
10 voting on three separate, it sounds like the
11 reliability testing would be sufficient for all
12 three to be done en bloc, are we okay with that?
13 So let's vote for all three in one vote. I mean
14 --

15 MS. CHAVEZ: So one vote for all three
16 domains?

17 (Simultaneous speaking.)

18 CO-CHAIR BROOKEY: Are we okay with
19 that? Okay.

20 MS. CHAVEZ: Okay? So we're voting on
21 reliability for all three domains for the ADAPT
22 survey measure. One high, two moderate, three

1 low, four insufficient. Voting's open.

2 (Pause.)

3 MS. CHAVEZ: Twenty-four.

4 CO-CHAIR BROOKEY: Moderate, yes.

5 MS. CHAVEZ: Okay.

6 CO-CHAIR BROOKEY: Okay.

7 MS. CHAVEZ: Zero voted high, 19 voted
8 moderate, five voted low, zero voted for
9 insufficient.

10 CO-CHAIR BROOKEY: Great. So we
11 talked, a little bit, about validity already, do
12 our members, expert members want to comment on
13 validity? And just to remind you, that would be
14 Marlene, Amy, or Kerri. If not, do the
15 developers want to comment?

16 DR. SAWICKI: I think that, in terms
17 of validity, if you're going to think about them,
18 as three separate domains, the only difference
19 being that the third domain didn't undergo the
20 confirmatory factor analysis and other types of
21 voting, either the focus groups, the cognitive
22 interviews, the expert interviews, all the things

1 that, sort of, went into face validity is there
2 for all three.

3 CO-CHAIR BROOKEY: Okay.

4 DR. SAWICKI: The third, the third
5 domain, it's about specific transition plan and
6 was a transition plan discussed and given? And
7 we know that that's a strong recommendation from
8 many groups, professional groups and
9 organizations, and we understand that there's a
10 similar to a previous discussions today around
11 care plans. We know that there is some rationale
12 for thinking about care plans. And in the end,
13 for an adolescent who is transitioning to adult
14 care, having a care plan is important for them
15 and may not be, as important, for their parents,
16 particularly, in certain situations, and so even
17 though we're unable to do the, sort of, construct
18 validity testing, because of the numbers, that to
19 us, actually, indicates that it's even more
20 important to have such a measure in place.

21 CO-CHAIR BROOKEY: So I would
22 recommend that we vote -- Amy, do you have a

1 comment?

2 MEMBER HOUTROW: I have a comment
3 about validity. There were a number of
4 populations that were excluded from this, but one
5 that, for me that brings up a question about
6 validity for a very important population, again,
7 is those individuals who can't participate
8 adequately, who really do need transition
9 services, but can't participate in this survey,
10 and so those would be individuals, who are, can't
11 communicate, for whatever reason, or are
12 otherwise intellectually impaired.

13 DR. SAWICKI: We 100 percent agree
14 with that comment and we recognize that there is
15 a need of quality measurement around that
16 population and that population may, in fact, be
17 the most vulnerable. But, when we started this
18 process, we realized that there really isn't one
19 way to capture patient experience around all
20 adolescents and young adults with chronic
21 conditions and we would be remised to ignore
22 those that are cognitively able to transition,

1 they're a very important part of the population,
2 understanding that future work needs to focus on
3 those that have other developmental and
4 intellectual disabilities.

5 MEMBER HOUTROW: Do you see that, as a
6 threat to validity, at all? That you keep, are
7 missing -- they're not an exclusionary
8 population.

9 DR. SAWICKI: I think that, well, the
10 exclusionary population's inability to complete
11 the survey. And so it is, I don't think it's a
12 threat to validity at a, at a population level,
13 understanding what the population that you're
14 serving, is.

15 MEMBER HOUTROW: They're not excluded.

16 DR. SAWICKI: They are excluded,
17 meaning, if they get the survey and they cannot
18 complete it, they are, the parents are instructed
19 to not complete the survey.

20 CO-CHAIR BROOKEY: Yes that was my, I
21 wanted to clarify that. It's being mailed to the
22 parents, but the parents are being instructed not

1 to complete it, although, you can't really
2 prevent them from completing it?

3 DR. SAWICKI: In our field test, we
4 did have several families mail back the survey
5 with their comments saying, I'm completing this
6 form for my child, because they cannot, and we
7 excluded those from our analyses.

8 There, also, is a question, at the
9 end, which is very similar to other patient
10 experience surveys asking, if the individual
11 receives any help, so that kind of ability for
12 stratification could be done.

13 CO-CHAIR BROOKEY: That, I think that
14 helps. What I recommend -- oh. Jenny, go ahead.

15 MEMBER MOYER: The FECC question. So
16 the denominator here was kids, who were pediatric
17 care?

18 DR. SAWICKI: So the denominator is
19 slightly different for the three domains, but the
20 denominator for who was actually sent the survey,
21 are children, who are 16 and 17 years old. And
22 so the assumption is that they're in pediatric

1 care.

2 MEMBER MOYER: Okay, because 40
3 percent of kids that age see family practitioners
4 --

5 DR. SAWICKI: So, so it --

6 MEMBER MOYER: -- not pediatricians.

7 DR. SAWICKI: So they could be in
8 family practice care, or other types of general
9 practices. It was, the way the sample is
10 constructed is by using health plan data to
11 identify children with medical complexity.

12 An organization could choose to field
13 surveys in different ways, but it's not
14 restricted to just the pediatric, or
15 pediatrician.

16 CO-CHAIR BROOKEY: Ricardo.

17 MEMBER QUINONEZ: Just some guidance.
18 So since validity does take into account some
19 evidence, does the assessment of the evidence
20 have to be different, because of the pathway we
21 went through when we assessed the initial
22 evidence?

1 (No audible response.)

2 MEMBER QUINONEZ: I mean, is it more
3 limited, is the bar higher, how do we --

4 MEMBER JOHNSON: I don't think it's
5 any higher.

6 CO-CHAIR SUSMAN: Yes, I don't see
7 that there's any difference in the way we've
8 considered validity in the past. You know,
9 basically, is this measure valid?

10 MEMBER QUINONEZ: Right, but one of
11 the things that I'd asked for measure
12 specifications are consistent with the evidence,
13 so that's why I'm asking about, whether our
14 assessment --

15 CO-CHAIR SUSMAN: Yes.

16 MEMBER QUINONEZ: -- of the evidence
17 should be any different?

18 CO-CHAIR SUSMAN: I would say no.

19 CO-CHAIR BROOKEY: I think --

20 MEMBER QUINONEZ: Like --

21 CO-CHAIR BROOKEY: I think you're
22 raising a process question that we need to take

1 back to NQF. I think we've already, kind of,
2 gone through this enough times, I think we need
3 to, sort of, voice our concerns about this, but
4 I, we're taking this pathway now and I think we
5 vote on the validity, as been reported.

6 DR. SAWICKI: One more clarification
7 for Dr. Moyer. In the third domain of the
8 transition planning, there's a specific question
9 that says, does your provider take care of mostly
10 children and teens, and if they say no, because
11 it's a family practice, they don't get a score
12 for that. So even though transition planning
13 needs to happen, from a developmental
14 perspective, the actual transfer is not expected
15 in that case, and we built that into that survey,
16 specifically.

17 CO-CHAIR BROOKEY: Thank you. I'm
18 going to recommend that we vote on one and two,
19 together, since they're similar, in terms of
20 validity, and then, 3 separately, if that's okay?
21 So it will be two different votes. We're now
22 voting for one of the first two domains. And

1 just to remind you, I've lost it on my screen
2 here.

3 MS. CHAVEZ: Okay.

4 MS. ALLEN: Before --

5 MS. CHAVEZ: Now --

6 MS. ALLEN: One second. Before we
7 start voting on validity, I just wanted to
8 clarify something, for the record, a vote was
9 miscalculated. So for reliability, the votes are
10 actually zero high, 18 moderate, five low, and
11 one insufficient.

12 CO-CHAIR BROOKEY: Okay, thank you.

13 MS. CHAVEZ: So we're voting on
14 validity for the first two domains, counseling on
15 transition self-management and counseling on
16 prescription medication. And this is for
17 validity and our options are one high, two
18 moderate, three low, four insufficient, voting is
19 open.

20 (Pause.)

21 MS. CHAVEZ: Twenty. Twenty-two.
22 Twenty-two. Twenty-three.

1 CO-CHAIR BROOKEY: One more.

2 MS. ALLEN: Lauren, we're waiting on
3 your vote.

4 (Pause.)

5 MS. CHAVEZ: Okay. So one voted high,
6 20 voted moderate, two voted low. The first two
7 domains pass validity.

8 CO-CHAIR BROOKEY: Thank you. All
9 right, the next vote will be on feasibility and
10 this is -- I'm sorry. I'm sorry, the third
11 domain. I got ahead of myself. So third domain.

12 MS. CHAVEZ: Okay, we're ready to vote
13 on the third domain, transfer planning on
14 validity, one high, two moderate, three low, four
15 insufficient.

16 (Pause.)

17 MS. CHAVEZ: Sixteen. Twenty-two.
18 Twenty-three. Twenty-four. Okay, zero voted
19 high, 15 moderate, six low, three insufficient,
20 and this domain passes validity.

21 CO-CHAIR BROOKEY: Okay, we'll move on
22 to feasibility, and I think we've talked a little

1 bit about the logistics, about the way the survey
2 is mailed out. We did talk about the way the
3 denominator would be populated, in terms of
4 getting health plan data.

5 This could, either, be a group, or
6 practice measure, or a health plan measure, I
7 believe, so are there other comments, or
8 questions, about feasibility, from the expert
9 group?

10 (No audible response.)

11 CO-CHAIR BROOKEY: Any concerns about
12 feasibility? You wanting to vote? Yes, Jenny.

13 MEMBER MOYER: Just the survey
14 response rate?

15 DR. SAWICKI: So in the three
16 different field tests in our pediatric hospital,
17 we had about a 45 percent response rate. And
18 then, in our Medicaid plans, it was 22 percent
19 and 28 percent.

20 MEMBER MOYER: Thank you.

21 CO-CHAIR BROOKEY: Which is very good.

22 So --

1 MEMBER FEI: I guess, my question is,
2 was there thought given to other methods, besides
3 mail?

4 DR. SAWICKI: So that came up on the
5 phone call, as well.

6 MEMBER FEI: Yes.

7 DR. SAWICKI: And that, we all know
8 that, for adolescents, coming up with electronic
9 ways of capturing data is, probably, a good way
10 for the future, and I think that moving forward,
11 thinking about capturing patient experience
12 measures, electronically, at the point of care,
13 in some other way that, particularly, for this
14 population of adolescents, I think it's
15 appropriate. We didn't do it in our field tests,
16 so we can't comment on how it --

17 MEMBER FEI: Right.

18 DR. SAWICKI: -- would have been
19 different, but certainly, it's something to be
20 considered.

21 DR. SCHUSTER: And I'll just add to
22 that, that we're doing other patient experience

1 work and we are, currently, testing another
2 survey using email, which feels like it would
3 have been a decade ago, but it's still a very new
4 idea in the patient and family experience fields.

5 MEMBER FEI: It's moving in the right
6 -- hey, it's all in the right direction.

7 CO-CHAIR BROOKEY: Are we ready to
8 vote? Okay. And are we going to vote, I don't
9 see any reason not to vote all three at once, is
10 that all right?

11 MS. CHAVEZ: So we're voting on
12 feasibility on all three domains?

13 CO-CHAIR BROOKEY: Yes.

14 MS. CHAVEZ: Okay. All right, one
15 high, two moderate, three low, four insufficient,
16 and voting is open.

17 (Pause.)

18 MS. CHAVEZ: Twenty. Twenty-two.
19 Twenty-four. One voted high, 19 voted moderate,
20 four voted low, and zero for insufficient.

21 CO-CHAIR BROOKEY: What's the use in
22 feasibility? All right, we're at the top of the

1 hour, and so I need to ask your permission, if we
2 can go a few more minutes. We have two more
3 votes. Can we go a few more minutes?

4 Okay. So we've got to use --

5 (Laughter.)

6 CO-CHAIR BROOKEY: Otherwise, you guys
7 have to come back tomorrow, right? So --

8 (Laughter.)

9 CO-CHAIR BROOKEY: Okay, we're going
10 to usability and use. And are there, from the
11 Committee Members, are there any comments, or
12 questions about use, usability and use?

13 MEMBER FEI: I don't, I don't
14 remember, from our call, but I know it hasn't
15 been used outside of your testing, is that
16 correct?

17 (No audible response.)

18 MEMBER FEI: Do you have a plan to use
19 it more widely? I know you did, you got pretty
20 wide results, so I thought that was good, but
21 beyond those settings, is there thoughts of using
22 --

1 DR. SAWICKI: So --

2 MEMBER FEI: -- small settings?

3 (Simultaneous speaking.)

4 DR. SAWICKI: Since this was
5 developed, as part of the AHRQ CMS, PQMP, it
6 became publically available. We've had over 80
7 groups inquire about use of the tool, you know,
8 this happened within the last six months, so we,
9 right now, don't have any way to know who is, or
10 is not, implementing, or using it, at this point.

11 CO-CHAIR BROOKEY: Comments,
12 questions? You want to vote? Okay, let's vote.
13 And, again --

14 MS. CHAVEZ: Okay, we're voting --

15 CO-CHAIR BROOKEY: Again, we'll go
16 ahead and vote for all three, simultaneously,
17 unless there's any objections?

18 (No audible response.)

19 CO-CHAIR BROOKEY: Okay.

20 MS. CHAVEZ: Okay. And we're looking
21 for 23 votes. One high, two moderate, three low,
22 four insufficient, voting is open.

1 (Pause.)

2 MS. CHAVEZ: Thirteen, 18, 21. Two
3 more. Twenty-three, thank you.

4 CO-CHAIR BROOKEY: All right, very
5 good.

6 MS. CHAVEZ: Three voted high, 16
7 voted moderate, two voted low, two for
8 insufficient, and those are the votes for all
9 three domains on usability and use.

10 CO-CHAIR BROOKEY: Okay, so the final
11 vote is on overall. And, I'll say it again that,
12 we've had a lot of discussion, I think, it's been
13 captured and will be taken back.

14 And so lots and lots of good comments
15 and suggestions. I appreciate all of you being
16 so keen on the words, because it really is, it's
17 challenging, because all of us, this isn't our
18 full-time job, but I think it's been a very
19 fruitful discussion, and we should move on to
20 this last vote of the evening for overall.

21 MEMBER MOYER: So this would be, if we
22 vote positively, then this would become a quality

1 measure, if it goes, if it gets through
2 everything else it has to get through?

3 CO-CHAIR BROOKEY: If it gets through
4 everything else.

5 MEMBER MOYER: Yes.

6 CO-CHAIR BROOKEY: If it gets through
7 everything else, it would be endorsed, but I can
8 tell you, there's many endorsed measures that
9 never really get put out there. So it, this is
10 the first place to go --

11 MEMBER MOYER: Certainly.

12 CO-CHAIR BROOKEY: -- to get put out
13 into the public. But, yes, there are other hoops
14 it has to go through, before it becomes endorsed,
15 and then, before it actually becomes --

16 MEMBER MOYER: Yes.

17 CO-CHAIR BROOKEY: -- in use.

18 MEMBER MOYER: And I, I want to point
19 out that, as much as I do, I actually like the
20 survey and I like the idea and I think
21 transitions are incredibly important, having
22 spent a lot of times in special needs clinic, I'm

1 a little uncomfortable that, that we're endorsing
2 a very specific survey, without having looked at
3 any other surveys that do the, that are aimed in
4 this same direction.

5 DR. SAWICKI: I don't know that there
6 really are any other experience --

7 MEMBER MOYER: I --

8 DR. SAWICKI: -- surveys.

9 MEMBER MOYER: I know of several
10 others, they just haven't ever been presented,
11 nationally. So and I, which isn't to say they've
12 tried to, tried to get them out there, but we had
13 one that we used at Texas Children's that was,
14 you know, and I didn't particularly like it.
15 That doesn't mean I like it any more, or less,
16 but I have a concern about, about endorsing a
17 very specific survey, rather than endorsing that,
18 so --

19 DR. SAWICKI: We, certainly, looked at
20 a lot of other measures that had been looked
21 through, a lot of them were parent report
22 measures and not youth report measures and we

1 adapted a lot of the questions in our, sort of,
2 development of this and so, you know,
3 particularly, the National Survey of Children
4 with Special Health Care Needs was one. And so,
5 so I mean, it's, I think there haven't been, I
6 don't think there have been any others that have
7 been directly adolescent reported.

8 MEMBER MOYER: Okay.

9 MS. MUNTHALI: So we just wanted to
10 clarify something. NQF does not endorse surveys.
11 What you are recommending for endorsement is a
12 measure that's based on this specific survey. So
13 we just wanted to clarify that, again, for the
14 record.

15 CO-CHAIR BROOKEY: And voting for all
16 three domains, at once, unless there's any
17 objection? Oh, I'm sorry, go ahead.

18 PARTICIPANT: He was voting.

19 CO-CHAIR BROOKEY: Oh, he was voting?

20 PARTICIPANT: He was already, yes, he
21 was eager to get out.

22 CO-CHAIR BROOKEY: Okay let's vote.

1 MS. CHAVEZ: Okay, is Measure 2789
2 suitable for endorsement? One yes, two no,
3 voting's open.

4 (Pause.)

5 MS. CHAVEZ: Eighteen. Twenty. We're
6 looking for 23 votes. Twenty-three, thank you.
7 Sixteen voted yes, seven voted no.

8 CO-CHAIR BROOKEY: All right, so thank
9 you very much. We're not done, yet, we have one
10 more decision to make.

11 We have a lot of work to do tomorrow,
12 and there's been a suggestion from the staff, not
13 from me, but from the staff, that we get an early
14 start. Would people be okay starting, we were
15 supposed to start at 8:00 a.m., is that correct?

16 MS. MUNTHALI: At 7:30 a.m., so I
17 don't know how much earlier we can start. But
18 there is breakfast at 7:00 a.m., if I'm not
19 mistaken.

20 MS. ALLEN: Breakfast is at 7:30 a.m.

21 MS. MUNTHALI: At 7:30 a.m.

22 MS. ALLEN: And the meeting starts at

1 8:00 a.m.

2 CO-CHAIR BROOKEY: Can we, can we
3 start breakfast earlier and start the meeting at
4 7:30 a.m.?

5 MS. ALLEN: Yes.

6 CO-CHAIR BROOKEY: Is everybody okay
7 with that? We're going to start the meeting --

8 (Off microphone comment.)

9 CO-CHAIR BROOKEY: Breakfast at 7:00
10 a.m., the meeting will start, promptly, at 7:30
11 a.m. And we will be out, promptly, by 3:00 p.m.
12 All right, good night, everyone.

13 (Whereupon, the meeting in the above-
14 entitled matter was concluded at 5:05 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: Pediatric Measures
Steering Committee

Before: NQF

Date: 12-01-15

Place: Washington, DC

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