NATIONAL QUALITY FORUM

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NATIONAL VOLUNTARY CONSENSUS STANDARDS
FOR PATIENT OUTCOMES

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CHILD HEALTH STEERING COMMITTEE

WEDNESDAY,
MAY 5, 2010

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The Steering Committee convened at 9:00 a.m. in Suite 600 North of the Homer Building, located at 601 13th Street, N.W., Washington, D.C. Charles Homer and Marina L. Weiss, Co-Chairs, presiding.

PRESENT:
CHARLES HOMER, MD, CO-CHAIR
MARINA L. WEISS, PhD, CO-CHAIR
DAVID R. CLARKE, MD, MEMBER
SHARRON DOCHERTY, PhD, CPNP (AC/PC), MEMBER

NANCY L. FISHER, MD, MPH, MEMBER
KATHY J. JENKINS, MD, MPH, MEMBER
PHILLIP KIBORT, MD, MBA, MEMBER
ALLAN LIEBERTHAL, MD, FAAP, MEMBER
THOMAS McINERNY, MD, MEMBER
MARLENE R. MILLER, MD, MSc, MEMBER (via telephone)

LEE PARTRIDGE, MEMBER
DONNA PERSAUD, MD, MEMBER
GOUTHAM RAO, MD, MEMBER
ELLEN SCHWALENSTOCKER, PhD, MBA, MEMBER
BONNIE ZIMA, MD, MPH, MEMBER
LISA BERGERSEN, MD
CHRISTINA BETHELL, PhD, MPH, MBA (via

telephone)
JOHN BOTT, MSSW, MBA (via telephone)
NICOLA ELDRED-SKEMP (via telephone)

PRESENT(Cont'd):

MICHAEL MURPHY, EdD

NINA RAUSCHER, MD, RN

SCOTT STUMBO (via telephone)

NQF STAFF MEMBERS PRESENT:

HEIDI BOSSLEY, MSN, MBA

NICOLE McELVEEN, MPH

ASHLEY MORSELL

NALINI PANDE

SUZANNE THEBERGE

REVA WINKLER, MD, MPH

MEMBERS NOT PRESENT:

FAYE A. GARY, EdD, RN, FAAN, MEMBER

JANE PERKINS, JD, MPH, MEMBER

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

2 9:03 a.m.

3 MS. McELVEEN: Good morning, good
4 morning. Welcome to the Child Health Outcome
5 Steering Committee meeting.

6 I think we have everyone from the
7 Committee here who will be attending for the
8 exception of one Committee Member, who will
9 actually be attending in person. I think it
10 is Ellen Schwalenstocker. I don't think she
11 is here yet.

12 We also have a few Members who are
13 going to be calling in and joining us on the
14 phone as well.

15 My name is Nicole McElveen. It's
16 nice to finally put faces to names here. And
17 I am joined by a few NQF Staff: Reva Winkler,
18 of course, Heidi Bossley, Suzanne -- pronounce
19 your last name for me.

20 MS. THEBERGE: Theberge.

21 MS. McELVEEN: Theberge. And
22 Ashley Morsell is also working on a project.

1 Also, we have Charlie Homer and
2 Marina Weiss who are our lovely co-chairs on
3 this. So I'm just going to allow them to make
4 a few welcome and introduction comments and
5 then we will go ahead and have the Committee
6 introduce themselves and move forward from
7 there. And be sure to use the mic.
8 CO-CHAIR HOMER: I remind you to
9 press the button. The main reason I did that
10 was to demonstrate the inappropriate and then
11 the appropriate way for speaking.
12 But, welcome everyone. It's great
13 to see you. We do have a lot of work to do
14 over the next two days. I'm very excited
15 about it. I just want to at least let you --
16 reemphasize to you my sense of the importance
17 of the work that we are doing here.
18 This is one of the key committees
19 that is looking at outcomes. It's one of the
20 important committees that is starting to
21 develop a comprehensive set of measures for
22 children's health care. So we are really

1 ground-setting, I think, in both of those
2 areas. So very excited about it.
3 We have got a very diverse set of
4 measures we are going to be looking at, things
5 that are from, you know, quite technical,
6 hospital-based measures to quite less
7 technical, broad community-based outcome
8 measures, which is what we asked for when we
9 first met. So we got what we asked for and
10 now we have to make decisions about it.
11 So it should be fun. With that,
12 Marina?
13 CO-CHAIR WEISS: Well, I'm
14 delighted to welcome all of you to our two
15 days worth of very intense work on behalf of
16 NQF and moving these measures forward.
17 I would just say I agree with
18 everything that Charlie has outlined and the
19 only thing I would add is that NQF is a really
20 important player with regard to the consensus
21 process. And so this is a wonderful
22 opportunity for us to launch some pediatric

1 measures that, hopefully, will set the base
2 for future work as well.
3 There is a great deal of interest
4 in Congress and within the administration and,
5 hopefully, we will tuck into that agenda and
6 help set the pace not only for the pediatric
7 measures, but just for a more robust approach
8 to quality generally.
9 So it is terrific to be a part of
10 this NQF effort and thank you so much, Nicole,
11 for all the prep work that you and Reva did to
12 get us ready to spend two days working hard.
13 So thank you.
14 MS. McELVEEN: Okay. Just a few
15 housekeeping items. The restrooms are, as you
16 exit these doors to your right. There are two
17 keys located on that back table, if you need
18 to use the restroom.
19 Everyone has a thumb drive. That
20 basically has all of the materials that I have
21 emailed you over the course of the coming
22 weeks in one spot. You don't have to use

1 them, but it may make it easier, rather than
2 kind of fishing through emails and that sort
3 of thing.
4 The agenda: the copy of the agenda
5 that I sent you yesterday with the final
6 materials was an older copy. We have revised
7 it. So we just made some new copies and
8 handed that out to you also, you know, just so
9 you know.
10 And also, be sure to use the
11 microphones, as Charlie just alluded to, when
12 you are talking, that's basically so the
13 transcriber can hear the information and also
14 so the participants on the conference call
15 line can also hear as well.
16 So I would like to just have each
17 Committee Member introduce themselves and also
18 go through disclosures, if there are any,
19 amongst the Members.
20 MEMBER PERSAUD: Donna Persaud,
21 Dallas, Texas. And I have no disclosures.
22 MEMBER McINERNY: Tom McInerny

1 from Rochester, New York. No disclosures.
2 MEMBER KIBORT: Phil Kibort,
3 Children's Minnesota. No disclosures.
4 MEMBER FISHER: Nancy Fisher,
5 Seattle, Washington. No disclosures.
6 MEMBER CLARKE: David Clarke,
7 Denver, Colorado. No disclosures.
8 MEMBER JENKINS: Kathy Jenkins
9 from the Children's Hospital in Boston. I'm
10 the Chief Safety and Quality Officer for
11 Children's Hospital Boston. And we submitted
12 measures as a steward, the hospital did, and
13 the program for Patient Safety and Quality,
14 which I direct.
15 And I had indirect involvement in
16 all the measures we sent in and, for two of
17 them, more direct involvement. So I'm going
18 to abstain from all conversations related to
19 any of the measures which we stewarded.
20 I don't believe I have any other
21 conflicts with any of the other measures.
22 MEMBER PARTRIDGE: Lee Partridge,

1 National Partnership for Women and Families.
2 No disclosures.
3 MEMBER ZIMA: Bonnie Zima, UCLA.
4 No disclosures.
5 MEMBER DOCHERTY: Sharron
6 Docherty, Duke University Medical Center
7 representing National Association of Pediatric
8 Nurse Practitioners. No disclosures.
9 MEMBER RAO: Goutham Rao from the
10 University of Pittsburgh. No disclosures.
11 MEMBER LIEBERTHAL: Allan
12 Lieberthal, Kaiser Permanente, Panorama City,
13 California. No disclosures.
14 MS. THEBERGE: Hi, everyone. I'm
15 Suzanne Theberge. I'm a Project Manager here
16 at NQF.
17 MS. BOSSLEY: I'm Heidi Bossley,
18 Senior Director on Performance Measures here
19 at NQF.
20 MS. McELVEEN: Okay. Do we have
21 anyone who has called in? Committee Members?
22 MEMBER MILLER: This is Marlene

1 Miller, Vice Chair at Johns Hopkins Children's
2 Center.
3 MS. McELVEEN: Great. Thank you,
4 Marlene, for calling in. Anyone else? Okay.
5 So what we are going to do for the first 20
6 minutes or so is, we wanted just to provide a
7 recap of what we have done to date in the
8 project, essentially, and start to frame our
9 discussion over looking at outcomes and
10 process --
11 Well, we won't be looking at
12 process measures, but we really want to frame
13 the discussion when we are looking at outcome
14 measures and really talk about what an outcome
15 measure is, what the Committee kind of
16 discussed at the meeting in November to sort
17 of frame the call for measures, which
18 ultimately was the reason why we received some
19 of the measures we did. So I wanted to take
20 a few minutes and go through that.
21 Our meeting goals, obviously, are
22 to evaluate the standards that we receive

1 during our call for measures. The Committee
2 will be asked to recommend these measures for
3 endorsement moving forward in our consensus
4 process.
5 And also, another very important
6 deliverable is to identify gaps for outcome
7 measures in children. And we will set aside
8 time. That type of conversation probably will
9 come up as we go through each individual
10 measure, but we have set aside time at the end
11 of today and also tomorrow to look at gaps and
12 measurement.
13 So largely, the Outcomes Project
14 is funded by HHS and, as most of you all know,
15 there are three phases to the project. Phases
16 I and II are currently happening now. Phase
17 III includes child health and also mental
18 health.
19 Our focus is on cross-cutting and
20 condition-specific outcome measures. There is
21 currently limited availability of existing
22 child health outcome measures and so we are

1 here to expand that horizon a little bit and
2 also expand NQF's portfolio of measures in
3 that particular area.
4 To date, we have about 68 NQF-
5 endorsed measures focused on child health.
6 Approximately 25 of those are focused solely
7 on outcomes. So there is definitely some room
8 for adding to that number.
9 This slide illustrates, really, a
10 framework when you think about child health
11 outcomes and some potential domains and ways
12 of bucketing this information. And also, when
13 you look at these domains, this also serves as
14 a frame when you think of gaps as well.
15 So potential domains include age
16 groups, certainly, you know, adolescents to
17 neonatals. There is many different age groups
18 when it comes to children. Health status is
19 particularly important. Settings of care,
20 looking at hospitals, outpatients. And level
21 of analysis is particularly important when we
22 are looking at these measures.

1 Most of them are on a population
2 level. As you probably have noticed, a lot of
3 the survey measures are more on a population
4 level, not necessarily on a clinician or
5 provider level of analysis when we are looking
6 at measurement.
7 Reva, did you want to add any
8 further comments to that?
9 DR. WINKLER: The only thing I
10 would say to that is, NQF and HHS also are
11 particularly interested in measures at all
12 levels of analysis, not that the individual
13 measure could necessarily meet all of them.
14 There might be a couple of really good ones
15 that could be used at all levels.
16 But having a mixture of
17 population-level measures as well as provider-
18 level measures as well as clinician-level
19 measures provides NQF with a really robust
20 portfolio that can be used in a variety of
21 ways by different implementors. So all of
22 them are on the table.

1 CO-CHAIR HOMER: I just want to
2 say my sense is while it is unlikely that any
3 measure can apply to all of them, it seems
4 like it is a desirable attribute. That is, if
5 there were measures that applied to multiple
6 levels, that would be good, because that would
7 simplify the field.
8 Just maybe an observation, having
9 looked at most of the measures, my sense is
10 that many of the people who submitted measures
11 did not have a crisp idea of what this
12 question meant when they described what level
13 the measure applied to.
14 So I think that's something we, as
15 Committee Members, are going to have to make
16 our own judgments about and not necessarily
17 rely on what many of the stewards suggested.
18 MS. McELVEEN: We then moved to
19 data sources for outcomes. Patient or care-
20 provider reported outcome, a clinician-
21 observed outcome, those sorts of things, vital
22 signs, lab results.

1 This highlights what the call for
2 measures for the Child Health Outcomes
3 Project, what we actually looked for. And we
4 tried to bring this to your attention, because
5 this is really an output from the November
6 meeting where you discussed a lot of this
7 information.
8 So it was things such as: child
9 and family functioning, school attendance;
10 performance, physical fitness, symptom
11 improvement or relief, growth and development,
12 that includes cognitive, physical, social,
13 emotional growth, parent/patient-reported
14 outcomes, intermediate outcomes, such as blood
15 pressure or BMI percentile, patient or family
16 experience with care, behavioral change.
17 And we have a second slide here:
18 health services utilization, potentially
19 preventable adverse social outcomes, health
20 care-acquired adverse events, population
21 health indicators.
22 And one type of measure, in

1 particular, that NQF normally doesn't get is
2 health care sectors that share
3 responsibilities. And so that's looking at
4 schools, you know, the juvenile system.
5 I believe that we have a few
6 measures around schools, so those are fairly
7 new to our portfolio when we are looking at,
8 in terms of quality improvement and public
9 reporting and accountability.
10 Let me just go back a second.
11 Were there any questions so far? Yes?
12 MEMBER PARTRIDGE: Nicole, as you
13 ran through that list, that page and the page
14 before, there are some measures in there that
15 I think we all thought we would get, but we
16 didn't. And do you have any sense? I mean,
17 there are three or four that look like no-
18 brainers. Are they not out there?
19 DR. WINKLER: I think, Lee, that's
20 the question. Do you know of specific
21 measures or specific good ideas? And I think
22 there are a lot of people that would agree

1 there are a lot of great ideas, but no one has
2 crafted the actual measure yet.
3 Certainly, we used all of your
4 contacts and everybody you could reach out to
5 and they were not, you know, submitted. So I
6 think there is a certain unknown. There may
7 be measures like that being used at local
8 levels or within facilities for local quality
9 improvement, but perhaps that don't rise to
10 the level that they feel that would be
11 appropriate for submission to NQF.
12 So I think any number of those
13 would address or apply to various measures.
14 MEMBER JENKINS: You know, my
15 sense would be that there is two major
16 barriers to this process that, if one is
17 contemplating submitting measures makes it
18 more challenging. And one is the degree of
19 burden of the validation and the current use
20 of the measure. And the second one is the
21 seemingly strict requirement that it be
22 available for high-stakes measurement like

1 public reporting or P4P.
2 And depending on people's
3 interpretation of their measure on those two
4 axes, it can be a barrier to submission. So
5 those are very high bars if you take them
6 literally.
7 CO-CHAIR HOMER: I think there are
8 more measures. There are more outcome
9 measures, certainly, in the pediatric research
10 community that we haven't received. So I
11 think Kathy's hypotheses sound pretty credible
12 to me. But we didn't get them, so we will
13 have to think through afterwards what to do
14 and how to do that.
15 MS. McELVEEN: Okay.
16 CO-CHAIR HOMER: I just also
17 wanted to briefly emphasize the importance of
18 the gaps identification. I mean, all of us
19 have participated in projects where, you know,
20 there is always a section that says, "further
21 research is needed", and you come up with a
22 list of 20 things and you know deep in your

1 soul that nobody ever looks at that list again
2 and it's kind of frustrating.
3 I think, in this case, we are in a
4 better situation. If you look at, for
5 example, both CHIPRA Legislation and the
6 Health Reform Legislation, it charges NQF,
7 specifically the Health Reform Legislation,
8 for identifying gaps, basically, on an every-
9 three-year basis, and reporting those to the
10 Secretary of HHS, for the Secretary, then, to
11 fund measurement development activities.
12 So there is a pipeline here that
13 is clearly articulated from the gap
14 identification to, actually, measurement
15 development and then measurement use. So I
16 think it is more than the usual, oh, yes, we
17 didn't get these measures and buried them at
18 the bottom of our report.
19 DR. WINKLER: Let me just add one
20 thing to that. One of the activities that is
21 going on with the group within NQF that is
22 actually addressing that Directive from the

1 Secretary on Prioritization is, they actually
2 have gone back through all of our past reports
3 and looked at that section that may not have
4 been previously read and is now being read
5 quite intently to help formulate some of them.
6 So it may be a little delayed, but
7 all of that effort was not for naught. And so
8 we have been told by HHS from the very
9 beginning that the endorsement of measures is
10 important, but equally important. It is not
11 an afterthought. It's not the appendix. It's
12 not an add-on. It's the gaps analysis.
13 Because they are in a position to
14 use their resources to develop things
15 appropriately within all of their various
16 agencies within HHS. So it's very much an
17 important outcome of this project.
18 CO-CHAIR WEISS: And let me just
19 tag on to Reva's point and underscore for you
20 the fact that there is some overlap between
21 this Committee, obviously, and the group that
22 has been working with CMS and AHRQ on the core

1 measure set and then the second wave of
2 pediatric measures that were called for in
3 CHIPRA.
4 Now, the reason I raise this is
5 because it is, as Charlie said, not just a
6 matter of coming up with a laundry list of
7 items where further research is needed, but
8 there is development money also associated
9 with CHIPRA. The money is already
10 appropriated; it is available. And HHS is
11 interested in knowing where to deploy and
12 allocate these resources.
13 So we do have an opportunity here
14 not only to identify gaps, but, maybe, to
15 prioritize and give them some direction on
16 what we think, based on the expertise around
17 this table, are the most promising areas in
18 which to begin work.
19 DR. WINKLER: Which is sort of a
20 perfect segue to Nicole's next slide.
21 MS. McELVEEN: We will be looking
22 at CHIPRA measures. Currently, only about, I

1 believe it is, 6 to 10 of the full set of
2 CHIPRA measures are NQF-endorsed. So we are
3 being asked to look at the remaining set of
4 those measures and also additional process
5 measures for child health and to look at
6 endorsing those measures.
7 This project, obviously, is
8 closely related to what we are doing now. We
9 are looking to move forward with this project,
10 really simultaneously after we get over the
11 hurdle of endorsing and recommending our first
12 set of measures.
13 We are looking to just continue
14 the stream and to continue work directly into
15 the CHIPRA Project. Ideally, we would like
16 all of the current Steering Committee Members
17 to continue along with that process. That
18 does mean another in-person meeting and
19 evaluating another set of measures, but, you
20 know, we notice very quickly that the group
21 sitting in front of us is really sort of the
22 cream of the crop and the people that should

1 be at the table when it comes to child health.
2 And we are hoping, if you are
3 willing and if you, obviously, have the time,
4 to continue on with that process. And once we
5 are done with this meeting, we will follow-up
6 more definitively on dates and to, you know,
7 get your feedback on that.
8 The tentative start date was, we
9 are looking at July of this year. And when we
10 say "start", that means that we would start
11 with a call for measures. And, of course, you
12 all know that's a 30-day process. So
13 potentially, an in person meeting would be,
14 probably, about September or October of this
15 year and that's just kind of off the top of my
16 head. So I wanted to mention that to the
17 group.
18 The good thing that most Committee
19 Members and projects aren't able to do that we
20 will be is many of the measures that you don't
21 feel apply to this project and are real
22 process measures, we then could potentially

1 review those within the contents of the CHIPRA
2 Project.
3 And I know that's a challenge for
4 many Committee Members. It's not appropriate
5 for this project, but you're kind of lost in
6 limbo and you don't really know what to do
7 with the measure, because you think it is
8 valuable, but there is potential for many of
9 the measures to be passed on and to move on
10 into this second phase of the project.
11 And so, when we are looking at
12 next steps, moving from outcomes to CHIPRA,
13 the gaps that you identify within the contents
14 of our two days here will be used,
15 essentially, in our call for measures and also
16 we will be sure to highlight a specific
17 section in the report, as we always do, to
18 highlight those gaps and areas where you think
19 there is room for improvement.
20 Are there any questions about
21 that?
22 CO-CHAIR HOMER: Flattery will get

1 you everywhere. The last Committee I think I
2 was on with Reva was NQF's longest serving
3 Steering Committee or whatever it is. So I
4 have been working it for the duration.
5 DR. WINKLER: Right. It went on
6 for three and a half years.
7 CO-CHAIR HOMER: Yes. I do have a
8 question though. So I'm a little -- I mean,
9 the CHIPRA measurement set is a defined
10 measurement set, at this point. They are the
11 twenty-some odd, 22, 24 measures. So there
12 will be a call for additional process and
13 outcome measures beyond the CHIPRA set?
14 MS. McELVEEN: Yes.
15 CO-CHAIR HOMER: To fill in the
16 gaps for the areas that the Committee
17 knowledge wasn't there?
18 DR. WINKLER: My understanding is
19 even though we have got the first year of core
20 measures, there is an acknowledgement that it
21 really is -- there is lots of gaps and it just
22 doesn't meet everyone's needs.

1 And there is a desire to evolve it
2 over the subsequent years and add in better
3 measures, remove the ones that are maybe not
4 so good or replace them, revise them, update
5 them whatever, so that there is an evolution
6 of that measure set. And so this will be an
7 important input to the next year's set.
8 CO-CHAIR WEISS: Well, let me just
9 say that the first wave of measures called for
10 under CHIPRA were selected in part because of
11 the speed with which the legislation
12 contemplated implementation.
13 And so a great deal of attention
14 was given to what is currently going on in
15 states today. What would be relatively easy
16 to get up and operational at the
17 implementation level? What were the measures
18 that were most comfortable for the state
19 officials who were sitting around the table
20 and so forth?
21 But there was always an
22 expectation that there would be future phases

1 to that project and, as Reva said, correction
2 and strengthening of the set of measures that
3 would ultimately be used.
4 Initially, these are to be
5 voluntary, but over time the direction is to
6 make them mandatory or at least a subset of
7 what is available and mandatory.
8 MEMBER PARTRIDGE: I would just
9 add a postscript to that, because Marina was
10 on that Committee and I sat in a chair behind
11 her for several days listening to their
12 deliberations and I think you had -- I forget
13 what you called it, the list, putting
14 everybody on the alert that the Committee was
15 looking for, hoping to see measures on
16 something else.
17 I also wanted to share something,
18 another opportunity for us, and I think this
19 plays in very nicely, that the CHIPRA
20 legislation does direct the Secretary to
21 report to Congress on some areas in which,
22 perhaps, there are some impediments to

1 effectively getting measures adopted and
2 satisfactorily used.
3 And CMS is being very open about
4 saying they would love to have comments in
5 whatever form that would help inform that
6 report, which they will be pulling together
7 some time later this year. So I think
8 probably things like our reports and
9 discussions will be useful.
10 MEMBER MILLER: Charlie?
11 CO-CHAIR HOMER: Yes, please.
12 MEMBER MILLER: This is Marlene
13 and I just want to add that I think if we go
14 on and I serve on a Committee that may know
15 the new four measures in the conversation
16 there and it strikes me that looking at the
17 materials we have before us that one of the
18 things that is not explicitly called for, but,
19 you know, I at least would like to see that we
20 entertain it, is that for any measure I
21 applaud the focus on outcomes, that we need to
22 also ask ourselves are there changed packages

1 that if an institution or a state or a
2 provider or a health plan is not performing
3 well, you can direct them on what to do to
4 actually change that rate.
5 You know, I think a lot of the
6 measurement work is measurement for
7 measurement's sake with the hopes that just
8 measuring will improve care.
9 And what we know is that that's
10 not necessarily true. That we need an actual
11 tool kit. When I even look to NQF
12 evaluations, it is sort of implied there, but
13 there is no explicit places that say, list the
14 packages that you know or the efforts that you
15 know have shown to change someone's rate and
16 improve it, so that you give people tools.
17 CO-CHAIR HOMER: That sounds like
18 a great suggestion. It's really NQF criteria.
19 I mean, again, the definition says the
20 measures have to be used for both
21 accountability and improvement, but you're
22 right, there is not much in there to back that

1 up.

2 That sounds like a very, very good

3 suggestion, Marlene. Thank you.

4 MEMBER MILLER: Okay.

5 CO-CHAIR HOMER: If I could just--

6 you know, I want to make sure we stay on

7 schedule. I think we have had a good, broad,

8 forward-reaching conversation and I didn't

9 hear anybody in the room say, "Oh, my God, I

10 don't want to be on the follow-up Committee,"

11 but you could certainly talk to Nicole

12 afterwards, if that's the case.

13 This will be a negative check-off

14 process. What is that, benign paternalism?

15 Isn't that what -- anyway, I do want to

16 reframe us, though, back to outcomes for a

17 second -- not for a second, for the rest of

18 the meeting. So while looking forward, we are

19 going to be discussing process measures once

20 we get to July.

21 Right now, we are focused on

22 measures of outcome. And I just want to

1 remind the group that measures of outcome are
2 selected because they are what is most
3 meaningful to patients, most understandable to
4 the public. It is what providers hope they
5 are influencing.
6 They don't measure everything
7 upstream that leads to the outcomes, so those
8 of us in the room who have been involved in --
9 who either are responsible for hospital or
10 clinical operations, sometimes get nervous
11 when we see an outcome measure, because we
12 think of the 43 other things that could
13 contribute to those outcomes.
14 And the answer is, kind of, we
15 know that, but we are supposed to come up with
16 measures of outcome that can be used together
17 with other measures of processes and maybe
18 even structures that could lead to those
19 outcomes.
20 But I say that, in part, because
21 my sense on our phone call with some very
22 complicated measures, which we are about to

1 segue into, there was some discomfort, really,
2 about looking at outcome measures because it
3 didn't measure the upstream characteristics.
4 And so I just want to reframe us
5 back on our particular charge, whether we
6 agree with it, you know, whether we have
7 anxiety about it or not, but our particular
8 charge is to identify and potentially endorse,
9 if we think they are of credible measures,
10 measures of child health outcome. Kathy?
11 MEMBER JENKINS: Thanks for saying
12 that, Charlie, because I think that's helpful
13 to me. I did have a question though, because
14 when I looked at some of the ones that were
15 assigned to me, some of them did feel more
16 like structural and process measures.
17 And then, I just heard your
18 comment that, where those come up, perhaps we
19 could set those aside for Phase II, if they
20 are not truly outcome measures.
21 I guess I was under the impression
22 that the NQF staff had screened what we were

1 getting for eligibility for this project, so
2 that those would have been filtered off. And
3 at least, the approach I took was to kind of
4 assume, since you had given them to me, it was
5 my job to kind of assess them according to the
6 criteria.
7 But, if that's not the rules, I
8 would like to hear us, you know, kind of set
9 all that for the entire discussion, because I
10 think it may come up in little ways across the
11 board.
12 DR. WINKLER: And just,
13 essentially, what we have is a moving target,
14 because at the time we did the call for
15 measures, we were intentionally very, very
16 broad. And our interpretation for them were
17 really quite broad.
18 The advent of the CHIPRA Project
19 and approval for going forward with that is a
20 relatively -- came afterwards. So we are
21 adjusting, as you will.
22 So if you feel particularly that a

1 measure is strong in and of itself, but isn't
2 appropriate for outcomes, we do have an avenue
3 to deal with it.
4 And so we were very loose in terms
5 of screening anything out prior. Again,
6 because two slides worth of how you describe
7 outcomes gave us pretty squishy borders. And
8 so our default was to keep it, rather than
9 kick it.
10 CO-CHAIR HOMER: I took your
11 approach. I had the same impression you did,
12 Kathy, and I took a different approach, which
13 is, I thought clearly if it was a process
14 measure and we were doing outcomes, I felt it
15 was inappropriate for us to list as an outcome
16 measure and that we would move it into
17 whatever other committee's place it was to
18 deal with. That was my own take.
19 CO-CHAIR WEISS: Let me just
20 observe, I guess, that the funder for this
21 project is CMS and they, of course, have
22 responsibility or HHS and CMS is intensely

1 interested in the outcome of these
2 discussions.
3 I just raise that because what we
4 are talking about, when CMS is in the room, is
5 Medicaid, CHIP and a very large percentage of
6 children with special health care needs and
7 also a very large percentage of children with
8 very good health.
9 So, to the extent that these
10 measures are going to make their way into use
11 with those programs, Congress will be very
12 interested in how well their investment is
13 being expended.
14 Meaning, therefore, that this
15 discussion we are having about differentiating
16 between outcomes measures and process measures
17 is extremely important. And my own sense is
18 that if the group around the table begins to
19 frame up the issues in an appropriate way,
20 that that will essentially be a teaching tool
21 for the very policymakers who are making
22 resources available to continue this project.

1 MS. McELVEEN: One other thing
2 that I just wanted to mention with the CHIPRA.
3 Suzanne will be staffing that portion of the
4 project, so I just wanted to let the Committee
5 know that. And I also noticed that Ellen has
6 joined us.
7 Did you want to just quickly
8 introduce yourself and, if you have any
9 disclosures?
10 MEMBER SCHWALENSTOCKER: Yes, my
11 name is Ellen Schwalenstocker. I'm Acting
12 Vice President for Quality Advocacy and
13 Measurement at the National Association of
14 Children's Hospitals and Related Institutions,
15 which is local, which is why I'm late, because
16 I was fighting with the D.C. traffic.
17 And the only disclosures are, as
18 an employee of NACHRI, we do have data
19 programs that do produce measures. We do not
20 have any in this particular group of measures.
21 MS. McELVEEN: Thank you. I
22 wanted to just quickly go through our

1 endorsement criteria. I know you have seen
2 this plenty of times, but it is worth just
3 refreshing. And also, I'll review with you
4 our options for recommending measures for
5 endorsement.
6 So again, our criteria, we're
7 going to be looking at importance, which is a
8 must-pass criterion and that's where a lot of
9 the discussion will come up is, is this an
10 outcome, is this a process measure? So that
11 will really happen in importance.
12 If it is not important to
13 measurement report and if it is out of scope
14 for this project, we do not continue with the
15 rest of the evaluation.
16 We next look at scientific
17 acceptability and the measure properties,
18 which covers a lot of the specifications of
19 the measure, obviously. Usability, a lot of
20 the discussions in terms of the level of
21 analysis will probably come out when we get to
22 usability and also feasibility.

1 The other thing I wanted to
2 mention is, when you are discussing the
3 measures, it will be sort of a balance and
4 tradeoff in terms of identifying why you like
5 or do not like the measure. So we encourage
6 the Committee Members to really stick to this
7 criterion and identify if, at all possible,
8 within these four criterion what specifically
9 was it that propelled you to recommend it for
10 endorsement or to not recommend it for
11 endorsement.
12 So again, this goes to those four
13 criterion again.
14 The evaluation process, you have
15 the measures and you have gone through most of
16 this already. As I mentioned, the measures
17 have to pass importance to continue remaining
18 in our process to be fully evaluated. And
19 what we will do is, we will vote on each of
20 those four main criteria and also receive a
21 vote overall on the measure, whether you
22 recommend it for endorsement or not.

1 Here are the options. Obviously,
2 recommend for endorsement, do not recommend
3 for and also recommend with conditions. That
4 should be used carefully. Recommending with
5 conditions means that you have specific things
6 that you would like the measure developers to
7 change about the measure.
8 So if it's a timeframe that is
9 unclear, if they need to clarify the
10 timeframe, if the specifications can be
11 cleaned up a little bit, there are certain
12 measures in which the Committee can provide
13 that recommendation. The conditions have to
14 be clear and we give the measure developer/
15 steward about two weeks to do that.
16 So your conditions shouldn't be
17 something that would completely change the
18 measure in any way. And they would follow-up
19 with their feedback and responses to those
20 conditions. We then would bring that back to
21 the Committee and you would review them and
22 decide from there whether you want to

1 recommend it for endorsement.

2 The other thing that may arise is

3 time-limited endorsement. This only applies

4 to untested measures. And we do have a small

5 handful of untested measures in our complete

6 set.

7 Recently, NQF has updated their

8 Time Limited Endorsement policy and there are

9 three specific conditions that must be met in

10 order for it to qualify for time-limited

11 endorsement: there cannot be a currently NQF-

12 endorsed measure that addresses the same topic

13 of interest, a critical time line must be met,

14 example, includes a legislative mandate for

15 this particular measure, and the measure

16 cannot be complex, so a composite or any

17 measure requiring risk adjustment would not

18 apply.

19 Also, there is a time period that

20 the measure steward must agree with to

21 complete the testing and that's 12 months.

22 Previously, it was 24 months. So I just

1 wanted to make the group aware.
2 And once we get to those measures
3 where this could be a possibility, certainly,
4 we will bring that to your attention and be
5 able to answer any questions about that.
6 Lastly, which we may revisit
7 again, it's just our timeline. Again, after
8 this meeting, we are scheduled to go out for
9 public and member comment in June, member
10 voting followed by that in August/September,
11 and CSAC review and Board endorsement in
12 October of this year.
13 So that's our tentative time line
14 and I just wanted to go through that quickly
15 with the group. Were there any questions?
16 Questions may arise as we go through the
17 measures. Kathy, did you have a question?
18 MEMBER JENKINS: I had a question.
19 I heard the part earlier about the next phase
20 of the project. Are you all anticipating
21 there will be another call for outcome
22 measures later or is it just the CHIPRA part?

1 DR. WINKLER: Actually, what NQF
2 is doing is revisiting with our Board of
3 Directors today actually. Our approach for
4 looking at measures realizing that trying to
5 reconcile what we have and new measures that
6 need to come in is not well-served with sort
7 of the kind of project focus, whether it's an
8 outcome with this or that.
9 So what we are hoping to move into
10 is sort of a rolling, you know, predictable,
11 every couple of years, there will be a call
12 for all measures around a certain topic area,
13 for instance, child health. And it wouldn't
14 be just outcomes, wouldn't just be process,
15 wouldn't just be hospital. And so we could
16 really look at that aspect of the portfolio in
17 a more comprehensive way.
18 So again, this is sort of an
19 evolutionary thing. So answering your
20 question, is it something we are able to do
21 right now? We are hopeful that it will be
22 something regular and predictable that will

1 have a stream to be bringing in new measures,
2 particularly when there is a big push for
3 measure development to occur.
4 Heidi, did you want to add
5 anything to that?
6 MS. BOSSLEY: I think we will know
7 when the Board decides today. But the hope is
8 to, again, have committees not look at this
9 one off-piece, here is a few outcome measures
10 that address one condition. Really perhaps
11 get our arms around what does care
12 coordination mean across the board, not only
13 looking at measures that are appropriate for
14 nursing homes when you deal with falls, but
15 also just falls in general across every
16 setting.
17 So the hope is to be able to
18 really start looking at comprehensive care
19 process, outcome structure, whatever, you
20 know, we can get and again build it into our
21 measure development and endorsement agendas.
22 That's the hope.

1 MS. McELVEEN: Okay. We are going
2 to segue into briefly reviewing the
3 Committee's discussion and votes on the four
4 AHRQ measures that were discussed via
5 conference call.
6 And in your packet of materials,
7 you will find a folder in there. Actually, it
8 is a PDF that has the meeting summary from our
9 April 12th conference call and further down,
10 it should be about page 5, we have compiled
11 the results from the Committee's vote on the
12 four main criterion and also the vote on the
13 recommendation for endorsement along with
14 several comments for each measure.
15 Let me see if I can enlarge this.
16 CO-CHAIR HOMER: The name of the
17 file is?
18 MS. McELVEEN: The name of the
19 file is CH Vote/Summary AHRQ Measures. So I
20 have it projected here.
21 CO-CHAIR HOMER: You're on page 5?
22 MS. McELVEEN: Yes, five, yes.

1 Let's see. So we wanted to take some time to
2 really briefly discuss this again. I know,
3 based on the results we got so far, we had
4 about 11 responses.
5 Essentially, the first measure
6 which was on urinary tract infection admission
7 rate, that measure and also the diabetes
8 short-term complication rate, those two
9 particular measures -- so far the majority was
10 do not recommend.
11 So I wanted to just kind of get
12 your thoughts about that and maybe re-vote,
13 because we only had an 11 vote, we have about
14 17 on the Steering Committee, and touch base
15 on those two measures first and then we will
16 go through the other two, which were more
17 likely to pass.
18 CO-CHAIR HOMER: Right. And had
19 fewer votes.
20 MS. McELVEEN: Yes. So this
21 first, the urinary tract infection admission
22 rate. The description is just the admission

1 rate for urinary tract infection in children,
2 ages three months to 17 years-old. Again,
3 this is a population level measure.
4 It looks like most of the
5 responses did agree that this was important to
6 measure and report. But when we looked at
7 scientific acceptability, usability and
8 feasibility, moderate was the rating overall
9 for those. And 8 out of 11 that reviewed this
10 measure requested not to recommend the
11 measure.
12 Two, recommend with conditions.
13 The comments weren't too specific on what
14 those conditions would be, so we can talk
15 about that, if that's something that we want
16 to do.
17 Also, I wanted to find out, do we
18 have AHRQ on the phone?
19 MR. BOTT: Yes. Hi, this is John
20 Bott with AHRQ.
21 MS. McELVEEN: Okay. Great. I
22 just wanted to make sure. I just wanted to

1 open it from the discussion with the group.
2 If there aren't any follow-up comments about
3 the measure, we can go right into voting on
4 the criterion, but I wanted to kind of get
5 your feedback and allow you to discuss any
6 concerns you had first.
7 CO-CHAIR HOMER: My recollection
8 of the major concern was people were not
9 convinced that there really was a
10 preventability dimension to the UTI issue.
11 Although, it is routinely included in the
12 ambulatory care sensitive conditions, which is
13 where this comes from, I think my sense of the
14 discussion was that we were not convinced.
15 Many of us reviewing this were not convinced
16 that ambulatory care processes, that there was
17 a clear link between ambulatory care processes
18 and this particular outcome.
19 MEMBER RAO: I think the age range
20 was a real concern for a lot of people, too.
21 I think that was a big one.
22 CO-CHAIR HOMER: So is there any

1 need to re-vote or do you want to call a
2 formal --
3 MS. McELVEEN: I would like to.
4 CO-CHAIR HOMER: So why don't we
5 call a formal vote then on this? If there are
6 no other questions or discussion of the
7 measure.
8 MEMBER JENKINS: Charlie, could I
9 ask in terms of your first comment, back to
10 our discussion about processes and outcomes
11 and whether or not all the pathways to the
12 outcome need to be clear in order for an
13 outcome to be important. If people are not --
14 I just want to be sure I understand the ground
15 rules.
16 If people aren't -- what you said
17 is that the major discomfort was that people
18 were not confident that ambulatory care
19 processes could prevent this outcome. Is that
20 crucial to the vote or is it really just is
21 this outcome important for child health? If
22 I can get that, because I'm struggling over

1 the criteria for what this Committee is about.
2 DR. WINKLER: I think you need to
3 look within the context of quality, because
4 these are -- we are looking to endorse
5 measures that are performance measures, that
6 are quality measures, so the outcome may have
7 a whole variety of inputs, but there should
8 be, at least, some reflection of the quality
9 of those inputs particularly around the
10 provision of the care.
11 And that's really the context we
12 are looking at. So there are a lot of very
13 important outcomes that may not reflect the
14 quality of care provided. It may reflect the
15 nature of the condition itself.
16 So there is a difference between
17 outcomes for which it is all about the
18 condition as opposed to outcomes for which we
19 see a lot of variation in care or variation in
20 the results that implies something about how
21 that care is delivered and sort of the large
22 quality context behind it.

1 CO-CHAIR HOMER: I think it is
2 tricky. It's a very --
3 MEMBER JENKINS: I would like to
4 clarify my question.
5 CO-CHAIR HOMER: Okay.
6 MEMBER JENKINS: I think I
7 understand that when we are living in the
8 scope of inpatient/outpatient care delivery.
9 But when we chose the scope of this project,
10 as a group, we also included these population-
11 based measures which have poverty and
12 disparities and parents and IQ and education
13 and SES and a lot of things that are not in
14 any way part of the process of care for
15 practitioners.
16 And so that's where I'm confused.
17 I understand your point when we are talking
18 about inpatient care/outpatient care/
19 ambulatory care, but not when we are in that
20 other space. And this was presented as a
21 population health measure, not as an
22 ambulatory care quality measure.

1 CO-CHAIR HOMER: I think your
2 point is well-taken. I don't think we are
3 going to be able to come up with a bright
4 line. I guess the way I think of it is if you
5 are looking at something like school days
6 missed, which is sort of an integrative
7 measure of a whole variety of things,
8 including, but not limited to health care, I'm
9 personally more willing to sort of allow that
10 kind of broad framing.
11 When you come up with really
12 something that still sounds like a clinical
13 measure, admission for UTI, now, that's my
14 take on it.
15 MEMBER JENKINS: Got it. That's
16 helpful.
17 CO-CHAIR HOMER: That's my take on
18 it, I'm not saying that's -- but that's how
19 I'm kind of differentiating these.
20 I think the other point that you
21 have raised though that there are other
22 technical reasons, like the broad age group,

1 which, you know, my wife being a judge reminds
2 me that sometimes if you can make decisions on
3 a narrow point, you don't go to the broad
4 point.
5 I don't know if we use those same
6 policies, but in this case, there is a narrow
7 technical concern about the switch. Maybe we
8 don't have to make the decision based on the
9 broader one.
10 DR. WINKLER: Charlie, let me just
11 follow-up with one thing. In terms of
12 population health measures, this actually is
13 a relatively new area that we are trying to
14 address. Population health is one of the
15 national priorities that was established.
16 We talked a bit about it in our
17 November meeting when Dr. Bonnie Zell, who
18 heads our population health efforts, talked
19 about that. It is slightly different and we
20 are actually learning and you are helping us
21 learn how we are going to address some of
22 these things.

1 NQF has previously endorsed some
2 population-based measures, primarily the
3 purpose of which was to provide context for
4 the environment in which health care is being
5 delivered. That was in our disparity
6 sensitive project.
7 So I think that the issues you are
8 bringing up are helping us learn the best
9 approach to look at population measures, but
10 there certainly is an audience and a demand
11 for looking at it that way.
12 Also, I think that there is a
13 sense that whatever happens at the individual
14 patient/clinician interface rolled up to
15 whatever larger provider group, those can be
16 rolled up to what is going on in your local
17 community. And rolled up, that would be the
18 ultimate ideal way of being able to look at
19 different levels of analysis and actually
20 inputs and potentially actions at various
21 levels.
22 MEMBER LIEBERTHAL: When I looked

1 at this measure, I said, it's interesting to
2 know, but I'm trying to -- and as I looked at
3 these other measures, especially the more
4 specific ones, such as this, I tried to look
5 at what conclusions can be drawn that would
6 lead to quality improvement.
7 And the implication of this
8 measure is that lower is better and for making
9 decisions for the individual child, lower may
10 not be better. So I think it is so broad that
11 the measure itself doesn't really add anything
12 to our ability to improve quality.
13 MEMBER MILLER: Charlie?
14 CO-CHAIR HOMER: Yes?
15 MEMBER MILLER: This is Marlene.
16 CO-CHAIR HOMER: Go ahead.
17 MEMBER MILLER: I would just add
18 my two cents. I think one of the
19 presentations I have on any area type level
20 measure is that, you know, the experience has
21 shown us that although measures get specified
22 for one thing, since there is -- once they are

1 approved in whatever group it is, there is no
2 stewardship, if you will, of maintaining that.
3 And so they have tended to then be
4 rolled down, despite the fact that though, for
5 example, if measures say this is not to be
6 held accountable at an institutional level.
7 They get rolled down because there is no one
8 that sort of stewards -- controls, if you
9 will, how entities use these measures.
10 So even though it's an area level
11 measure, it always raises concerns when
12 someone may start applying it at a health plan
13 level regardless. And those, you know, kind
14 of things have happened.
15 MEMBER FISHER: Can I add?
16 CO-CHAIR HOMER: Yes, please.
17 MEMBER FISHER: Can I add to what
18 she was saying?
19 CO-CHAIR HOMER: Of course.
20 MEMBER FISHER: I agree
21 wholeheartedly. And one of the -- also the
22 fact is that because this implies that lower

1 is better, if people apply it that way, we may
2 have an effect on quality that is decreasing
3 it rather than increasing it.
4 And so it's an unintended
5 consequence, but that's exactly what would
6 happen, because it would apply across the
7 board. And if you did it for younger
8 children, it would be worse, I'm just
9 assuming, than for older children.
10 So that's why I think the measure,
11 you know, isn't a good one for what we want to
12 do.
13 MEMBER RAO: Just to add, you
14 know, along that same point, I think the
15 measure could be acceptable and improved if it
16 was just a narrow age group and had specific
17 levels of severity.
18 I mean, obviously, for some kids
19 admission is appropriate. And if they had
20 said that they developed their measure around
21 that criterion, it would have been acceptable,
22 I think.

1 CO-CHAIR HOMER: Lee, did you also
2 --
3 MS. McELVEEN: Lee, did you have
4 something?
5 MEMBER PARTRIDGE: I think Dr. Rao
6 pretty much said what I was going to say. If
7 this had been focused on teens, for example --
8 MEMBER RAO: Yes.
9 MEMBER PARTRIDGE: -- I would have
10 had a very different reaction to it.
11 CO-CHAIR HOMER: Right. So I
12 think just in the interest of keeping us
13 moving forward, why don't we have a vote on
14 the measure as is and then we can make
15 recommendations to the steward if they choose
16 to -- that our suggestion, whether we want to
17 -- we can suggest to the steward that they
18 modify the measure and we would be happy to
19 see it again in the future, et cetera.
20 So why don't I call for a vote on
21 it as is. So why don't we start with the
22 negative, those who are opposed to endorsement

1 of this measure?

2 MEMBER MILLER: Charlie, my hand

3 is raised if you're raising hands.

4 CO-CHAIR HOMER: Okay. Great.

5 DR. WINKLER: 14.

6 MS. McELVEEN: Is that it? Thank

7 you.

8 CO-CHAIR HOMER: Any in favor?

9 MEMBER JENKINS: I would recommend

10 with conditions.

11 CO-CHAIR HOMER: Okay. One

12 recommend with conditions. Good. And were

13 there any abstentions? Good. Okay. So,

14 Kathy, do you want to tell us the conditions

15 that you think?

16 MEMBER JENKINS: The conditions

17 are that the measure be limited to population

18 measurement only and we age and gender

19 stratify.

20 CO-CHAIR HOMER: Do we want to

21 hear from the stewards thought on that?

22 MS. McELVEEN: John, did you have

1 any comments about that measure?
2 MR. BOTT: You mean specific to
3 the age and gender stratification?
4 MS. McELVEEN: Yes.
5 CO-CHAIR HOMER: Yes.
6 MR. BOTT: The measure is adjusted
7 based on age and gender and stratification is
8 possible at a number of levels, such as age
9 and gender and the software.
10 CO-CHAIR HOMER: Okay.
11 MEMBER JENKINS: My understanding
12 is the way the measure was put forward was
13 rolled up, but it was commented that it could
14 be age and gender stratified. So that was the
15 purpose of my comment, was that it should only
16 be presented age and gender stratified and not
17 rolled up.
18 CO-CHAIR HOMER: Sounds like it's
19 a moot issue. I think that reflects actually
20 the sense of the Committee is that is how it
21 should be done.
22 DR. WINKLER: I guess the question

1 is if that were to -- if they were to make
2 those changes, as Kathy suggested, would that
3 change the votes of the other Members of the
4 Committee from no to yes? It doesn't look
5 like it.
6 MEMBER PERSAUD: I would want to
7 see the age stratification.
8 MEMBER MILLER: Yes. This is
9 Marlene. I would want to see some data on
10 what that shows and the validity of it. I
11 know it changes the definition significantly.
12 You can't approve it and assume it still would
13 work right.
14 MS. McELVEEN: Okay. So we will
15 move on. I want to go to Measure 56. This is
16 the diabetes short-term complication rate.
17 Again, this was another measure where most of
18 the Members who reviewed and responded to this
19 survey voted not to recommend this for
20 endorsement.
21 A short description is just the
22 admission rate for diabetes short-term

1 complications in children ages 6 to 17 at per
2 100,000 population.
3 Comments?
4 MEMBER CLARKE: I just have one
5 comment. The discussion on page 3 of this
6 measure about the deliberations on the phone
7 suggest that a Committee Member recommended
8 adding first time admission for diabetes.
9 Actually, I was that Committee Member. And I
10 recommended excluding first time admissions
11 for diabetes.
12 And I believe Mr. Bott then said
13 that's really not possible because the coding
14 does not separate those two. So I just wanted
15 to clear that up.
16 MR. BOTT: That's a question for
17 AHRQ. Yes, the code doesn't offer that and
18 the measures that AHRQ developed, at the
19 present time anyway, didn't use the admissions
20 at a point in time. And that we are not yet
21 taking advantage of links to data sets where
22 we could perhaps link to previous admissions

1 and factor that into the denominator or
2 exclusions.
3 The world could change in the
4 future, but that's presently the data that we
5 are constrained with.
6 CO-CHAIR HOMER: So are there any
7 further discussions of this measure? If not,
8 then we can just call for a vote. Well, I
9 don't see any questions, so why don't we --
10 Kathy, comments?
11 MEMBER JENKINS: I guess the
12 comment I would make is once again at the
13 population-based level. The assumption would
14 be that the rate of Type I Diabetes is
15 relatively stable across population --
16 CO-CHAIR HOMER: Right.
17 MEMBER JENKINS: -- and across
18 regions. That problem, with the validity of
19 the measure, although real, may not actually
20 be influential in understanding variation. I
21 assume that's what the measure developer was
22 thinking in terms of that issue.

1 CO-CHAIR HOMER: So following on
2 that thought, if the prevalence of the disease
3 and prevalence of new cases, incidents of new
4 cases is the same across populations, then, in
5 fact, variation and hospitalization rate would
6 or could, in fact, be a reflection of care in
7 the community.
8 MEMBER JENKINS: Yes.
9 CO-CHAIR HOMER: Because if the
10 policies, in general, are to hospitalize, for
11 example, first new diagnoses, then that should
12 be stable across jurisdictions.
13 MEMBER JENKINS: And I would just
14 add that that's a general principle for risk
15 adjustment models where you are not always
16 able to adjust for every important confounder.
17 If an important confounder is relatively
18 stable and your unit of measurement is large
19 enough, that you could actually retain
20 validity without needing to adjust for that
21 unmeasurable confounder. And I see this as a
22 general issue as opposed to a specific issue.

1 MEMBER McINERNY: Charlie, is it
2 the place of NQF to recommend to the folks
3 that are doing ICD-10 that they make two
4 different codes? One for first time admission
5 and one for subsequent admission for diabetes?
6 Because that would be very helpful to us in
7 the long run.
8 CO-CHAIR HOMER: I would let the
9 people from NQF tell us that.
10 DR. WINKLER: We can certainly
11 include that as a recommendation, getting that
12 to the appropriate audience might be
13 challenging, but we can give it a try.
14 MEMBER McINERNY: Thank you.
15 CO-CHAIR HOMER: So why don't we
16 call for a vote then on this measure? So
17 again, this is the measure of admission rate
18 for diabetes in children age 6 to 17 per
19 100,000, so it's reported only as a population
20 measure, that is what it is specified as.
21 So all those, we will stay with
22 the negative, who recommend not endorsing?

1 MEMBER MILLER: I've got my hand
2 raised, Charlie.
3 CO-CHAIR HOMER: Okay.
4 DR. WINKLER: 10, 11.
5 CO-CHAIR HOMER: I think I'm going
6 to vote for this one. All those in favor?
7 DR. WINKLER: One, two, three,
8 four. Are there any abstentions? Did we
9 catch everybody? Microphone.
10 CO-CHAIR HOMER: Let's go back.
11 Let's go back to the --
12 DR. WINKLER: Yes.
13 CO-CHAIR HOMER: -- other
14 measures. The measure fails.
15 MS. McELVEEN: So we are going
16 back to Measure 55. This is measure
17 gastroenteritis admission rate.
18 Again, the age group is 3 months
19 to 17 years. And based on the Committee
20 Members who reviewed this measure and provided
21 their votes, six recommended it for
22 endorsement, two did not and there were two

1 that recommended it with conditions.

2 So this was more favorable, but I

3 can open it up for more comments.

4 CO-CHAIR HOMER: Ellen?

5 MEMBER SCHWALENSTOCKER: So my

6 only concern with this measure, and I like it

7 better than the other two, but, would be what

8 Marlene raised earlier, which is the potential

9 for misuse. So if I could be assured that it

10 was just going to be used at the population

11 level, I would feel comfortable with it.

12 But it seems to be a slippery

13 slope out there that sometimes measures

14 intended for one thing get used for another.

15 And my only worry is on unintended

16 consequences, i.e., keeping kids out of the

17 emergency room when that may be the only place

18 they can get care.

19 MEMBER McINERNY: This is one

20 where I think there is a place where the

21 measure can be useful in spurring QI

22 activities, because among the reasons for

1 admission are inadequate use of oral
2 rehydration, not having short-term holding
3 areas.
4 And I think that if this did
5 trickle down to the health plan or hospital
6 level or even provider level, that perhaps it
7 would induce some change in behavior that
8 would be a positive effect. So on that basis,
9 I think that this is a useful measure.
10 MEMBER MILLER: Charlie?
11 CO-CHAIR HOMER: Yes, go ahead,
12 Marlene.
13 MEMBER MILLER: This is Marlene.
14 I need to say my only experience is that I
15 work in an acute care clinic. I have seen the
16 exact opposite where it would not be good if
17 it trickled down, in that often times part of
18 the admission for this are very complicated
19 with psychosocial issues and parent
20 limitations and fragmented care and lack of
21 consistent caregivers.
22 And in that case, it is the right

1 thing, from a QI purpose, for a hospital to
2 admit that patient for the gastroenteritis
3 which comes up a lot and my population is, you
4 know, 85 percent is not more Medicaid. So at
5 least in my own experience, I'll say that it
6 is often times the right thing for the
7 hospital to actually admit the patient,
8 because of complicated social circumstances
9 that have failed out patient care.
10 CO-CHAIR HOMER: Okay.
11 MEMBER JENKINS: I would just
12 point out that at the population level, that
13 is still potentially preventable, so this is
14 a general concept that we have been discussing
15 in all of these places.
16 MEMBER MILLER: However, I would
17 say right back when you say that the
18 population level -- the interventions at hand,
19 it just get rolled out institutional level.
20 For me, to impact the psychosocial environment
21 are just not there. That goes right back to
22 my beginning point when we say we are going to

1 endorse measures.
2 I would like that all the measures
3 have a tool kit that you can hand folks. No
4 one likes to perform bad. People want -- if
5 they are going to have the condition, give
6 them the tools so that they know what to do
7 with it.
8 CO-CHAIR HOMER: But in this case,
9 there actually are -- I mean, there are --
10 there actually is a tool kit. Now, again,
11 part of the tool kit needs to be broader. In
12 other words, there are tool kits for oral
13 rehydration and management thereof, you know,
14 AP Guidelines, et cetera, around that.
15 I think the solutions we are
16 talking about for this would be also broader,
17 like some of the community transformation
18 activities that are written up in health
19 reform. But I think at least it is within the
20 range of concept that one can reduce at a
21 community level hospitalization for
22 gastroenteritis, you're right.

1 It would be unfortunate. You
2 wouldn't want the adverse -- you wouldn't want
3 a clinician at the front lines dealing with an
4 individual patient that they are concerned
5 about to have pressure put on them from
6 hospital administration, for example, that the
7 hospital would be dinged if they make the
8 right decision and admit a patient.
9 And that's what I hear from your
10 concern, which, you know, is a reasonable
11 unintended concern. But at the population
12 level, if you were comparing, you know, inner
13 city Baltimore to inner city Harlem, you know,
14 you would want to be able to compare.
15 You know, and again, I tried to
16 pick communities that would be of comparable
17 demographic status. You would want to be able
18 to compare how effective one community was
19 compared to another in their ability to
20 prevent something like this.
21 MEMBER MILLER: I totally agree,
22 Charlie. The problem is always that once it

1 is approved and out there, there is not
2 stewardship of how it is applied.
3 We may just end up getting rolled
4 down to a health plan at institutional level.
5 We may actually have negative impact on
6 quality of care.
7 CO-CHAIR WEISS: Stepping back
8 just a minute. I'm wondering if what this is
9 leading us to is a discussion about
10 presentation and maybe putting a tag line or
11 a footnote or some sort of statement together
12 with these population measures that makes it
13 abundantly clear that we intend for them to be
14 used in that way and in that way only?
15 CO-CHAIR HOMER: Yes.
16 DR. WINKLER: That's certainly a
17 very feasible thing to do when we write the
18 report, put it in a separate section of its
19 own labeled population measures and describe
20 the reasons for which they are approved.
21 Again, we can make that abundantly
22 clear in terms of the presentation as a

1 reflection of what your recommendation is and
2 limited to.
3 MEMBER McINERNY: Two points.
4 Number one, there is an upstream preventive
5 measure that would also reduce hospitalization
6 and that is the use or rotavirus vaccine and
7 how well that is being used.
8 CO-CHAIR HOMER: Well said.
9 MS. McELVEEN: Yes.
10 MEMBER McINERNY: Then the other
11 point though that I -- I think people may be
12 alluding to, but I want to make sure I
13 understand it correctly is, is there a concern
14 that a health insurance company would say,
15 hey, NQF has said children with vomiting and
16 diarrhea should not be admitted to the
17 hospital, therefore we will deny this
18 admission.
19 Is that sort of where we lose
20 control?
21 MEMBER MILLER: Yes, that's a
22 great example.

1 MEMBER McINERNY: Insurance
2 companies have been known to do that.
3 MEMBER JENKINS: But we are not
4 going to solve everything here at this
5 Committee.
6 MEMBER McINERNY: Right.
7 MEMBER JENKINS: I think that the
8 idea though, and I had asked this on the
9 phone, Charlie as my specific question to you
10 about these measures, was if they were being
11 proposed as population-based measures, would
12 the endorsement be limited to the use as a
13 population-based measure?
14 Because I can think of 1,000
15 confounders and problems if they get down to
16 too small buckets of patients. This is only
17 one.
18 DR. WINKLER: Yes. The
19 endorsement can be limited to the mass
20 population-based measures only certainly. I
21 mean, we have had other measures that are
22 appropriate only at certain levels of analysis

1 and that's what the endorsement is limited to.
2 MEMBER SCHWALENSTOCKER: So then
3 would that be a recommend with condition or is
4 that just okay?
5 DR. WINKLER: These are specified
6 as population level measures. So all you are
7 saying is yes and that's how that should be
8 used and that's the limit of our
9 recommendation.
10 CO-CHAIR HOMER: Well, one last
11 comment, because I'm conscious of the time and
12 how much we have to do over the next two days.
13 So go ahead, Lee.
14 MEMBER PARTRIDGE: I don't want to
15 prolong this discussion, but I did notice the
16 comments in the materials you sent out talked
17 a fair bit about the rotavirus and I don't
18 know that issue. I'm just wondering if it is
19 worth exploring for half a minute more what
20 its impact is and how it is mixed in here.
21 Is there a separate measure out
22 there of the use of rotavirus?

1 MEMBER PERSAUD: There isn't --
2 MEMBER PARTRIDGE: I don't think -
3 -
4 MEMBER PERSAUD: -- a separate
5 measure that we know of.
6 MEMBER PARTRIDGE: That's what I
7 thought.
8 MEMBER PERSAUD: What the
9 literature shows is that since the inception
10 of the virus now, I think, at least two full
11 years, that admissions for rotavirus,
12 gastroenteritis in toddlers, in particular,
13 has precipitously dropped and that is the
14 expected effect of the vaccine.
15 MEMBER PARTRIDGE: So presumably,
16 this is one case in which we might want to
17 have some recommendations of the Committee
18 down the line?
19 DR. WINKLER: Actually, the
20 rotavirus is included in the childhood
21 immunization NQF measure. I mean, NCQA
22 measure that is NQF-endorsed. So it has been

1 included since the vaccine has become
2 available. So it is already included in our
3 childhood immunization measure.
4 MR. GEORGE: Could I make one last
5 comment just addressing Tom's point there
6 about insurance companies using this measure
7 inappropriately?
8 I mean, do we need a statement
9 that says, for example, these measures are not
10 intended to be used as a clinical practice
11 guideline or as a clinical algorithm or is
12 there enough in the description of the
13 measures to counteract that?
14 DR. WINKLER: You're not talking
15 about something that is specific to these
16 measures, but is something that is ubiquitous
17 around performance measures in general. And
18 for the most part, usually the discussions are
19 talking about that the targets for any of
20 these measures are never zero or 100,
21 whichever, however the measure is crafted,
22 such that there is an acceptable level.

1 What we are looking for is
2 minimizing variation, minimizing extreme
3 outliers and trying to bring everybody to
4 whatever that acceptable appropriate level is.
5 And so it's not a black or white all or none
6 thing.
7 And that tends to be the
8 discussion that pervades all of performance
9 measurement.
10 CO-CHAIR HOMER: Did you have a
11 comment? No, okay. So why don't we vote on
12 this measure? I'll follow the same process,
13 just so people don't get confused.
14 So we will start with the
15 negative, that is all those opposed to the
16 endorsement of this measure signify by raising
17 your hand or saying something on the phone.
18 MEMBER MILLER: Something on the
19 phone.
20 DR. WINKLER: Marlene, your's is a
21 no?
22 MEMBER MILLER: Yes. Thank you.

1 CO-CHAIR HOMER: Anyone else no?
2 Okay. All those in favor of the measure?
3 DR. WINKLER: 13, 14, 15.
4 CO-CHAIR HOMER: Good. And no
5 abstentions then. Good.
6 MS. McELVEEN: Moving on. The
7 last measure in this set is the asthma
8 admission rate measure.
9 Again, the response to this was
10 favorable for endorsement. This is the asthma
11 admission rate for children ages 2 to 17. And
12 I'll open it up for comments.
13 CO-CHAIR HOMER: Any comments on
14 this measure or you feel like we have covered
15 the general discussion pretty well with the
16 gastroenteritis framing? Many of the same
17 concerns and issues.
18 Well, seeing no discussion --
19 MEMBER SCHWALENSTOCKER: Oh, one
20 thing.
21 CO-CHAIR HOMER: Ellen?
22 MEMBER SCHWALENSTOCKER: The

1 measure harmonization issue, can somebody
2 recall what that issue is?
3 PARTICIPANT: It's age.
4 MEMBER SCHWALENSTOCKER: It's age?
5 Oh, beginning at age 2.
6 DR. WINKLER: Yes, most of the
7 measures that offer asthma begin at age 5,
8 rather than at age 2.
9 CO-CHAIR HOMER: So is there any
10 way to address that or are we stuck with what
11 we have?
12 DR. WINKLER: Yes, let's ask John
13 Bott from AHRQ. Why was age 2 chosen for this
14 particular measure when, typically, measures
15 of asthma begin around age 5?
16 MR. BOTT: Yes. Unfortunately,
17 I'm not a clinician to be able to really
18 address that, but that's Patrick Romano's
19 question. And we didn't think there would be
20 much discussion today, so I told Patrick he
21 wouldn't need to participate today. So I'm
22 sorry, I can't personally answer that

1 question.

2 MEMBER JENKINS: I would imagine

3 the issue, Charlie, I assume you're going to

4 say this, is that there is sort of a

5 conventional wisdom that you can't diagnose

6 asthma before age 2. That line is often drawn

7 and I would imagine the people who came down

8 on the 5 year age range said, well, there is

9 some wiggle room between 2 and 5, so let's cut

10 it clean at age 5.

11 And you are just seeing both sides

12 of that in the older measures versus this

13 measure.

14 MEMBER FISHER: Or somebody got a

15 2 mixed up with a 5.

16 CO-CHAIR HOMER: No, I think the

17 clinical -- so I think in favor of it as

18 starting at the younger ages. Hospitalization

19 for asthma is, you know, very high at younger

20 ages and decreases as you get older. So if

21 you are trying to capture the largest number

22 of hospitalizations, you don't want to miss

1 the 2 to 5 year-old slot.
2 On the other hand, the clarity of
3 the evidence about the efficacy of, for
4 example, anti-inflammatories, the older ones
5 you hit the age 5 and up, you are clear you
6 are dealing with the inflammatory disease.
7 You are less confused with some of the others,
8 with small airways, et cetera.
9 So I think, you know, there is an
10 intersection here between crispness of
11 diagnosis and efficacy of therapy with the
12 older kids and the burden of disease which is
13 in the younger kids. And that's my guess is
14 why they ended up including the 2 to 5 year-
15 olds in this and not into the more clinically-
16 driven measures.
17 Allan, do you want to comment?
18 MEMBER LIEBERTHAL: Yes. Well,
19 one of the reasons that the NHLBI and most
20 asthma guidelines start at age 5, one of the
21 reasons is that's about the earliest that you
22 can do pulmonary function testing, which the

1 allergists really believe in, whether they
2 need to assure that or not, I don't know.
3 The other thing is I think that
4 under age 5, you are opening yourself up to
5 huge coding errors as to what was the real
6 reason for admission.
7 So any child who wheezes under age
8 5 might be diagnosed as asthma, whereas
9 wheezing is a secondary finding due to another
10 pulmonary problem under age 5. So I think it
11 is much -- even though it excludes a whole
12 large group of children, the convention of
13 over age 5, I still think should be used.
14 CO-CHAIR HOMER: Kathy?
15 MEMBER JENKINS: I would just
16 point out that this is again very similar to
17 the Type I Diabetes issue. I said before when
18 you are in the population-based arena across
19 large boxes of patients, that essentially
20 misclassification bias, which is what you are
21 alluding to on the 2 to 5 year-olds, if that
22 was equivalent across the country, for

1 example, or large geographic regions, then the
2 variation -- you could still understand
3 variation, despite that limitation, that real
4 measurement limitation that you are alluding
5 to.
6 MEMBER LIEBERTHAL: I don't think
7 that anybody has shown that it is consistent
8 across the geographic country or in the health
9 care system. I think that academic centers
10 may code one way and the community hospital
11 another way.
12 CO-CHAIR HOMER: It's a population
13 measure derived from discharge -- hospital
14 discharge data, right? I mean, that's where
15 you get it.
16 MEMBER JENKINS: Could we ask AHRQ
17 what they consider to be the geographic unit
18 of a population for the purposes of this
19 measure? Is it a state? Is it a region? I
20 assume it's not an institution.
21 MR. BOTT: No, it's not an
22 institution. It's typically a state, county,

1 something else that would end up at the
2 appropriate levels or, of course, with the
3 National Health Care Quality Reorganization.
4 CO-CHAIR HOMER: Okay. I think it
5 has been another excellent discussion, as they
6 all have been. Why don't we move forward with
7 the vote?
8 So all those, again, opposed to
9 endorsing the asthma measure as a population
10 measure? All those opposed? Three.
11 DR. WINKLER: Marlene?
12 MEMBER MILLER: Oh, sorry, I was
13 on mute. I oppose.
14 DR. WINKLER: Okay.
15 CO-CHAIR HOMER: Four.
16 DR. WINKLER: Four nos.
17 CO-CHAIR HOMER: All those in
18 favor of approving, endorsing the measure?
19 DR. WINKLER: One, two, three,
20 four, five, six, nine, ten. Ten yesses.
21 CO-CHAIR HOMER: So 10 to 4. Any
22 abstentions?

1 MEMBER SCHWALENSTOCKER: I'm not
2 abstaining, but I would recommend with the
3 condition that the age issue be looked at.
4 CO-CHAIR HOMER: All right.
5 MEMBER FISHER: That's a concern I
6 have, too.
7 CO-CHAIR HOMER: So from a process
8 perspective, the Committee, at this point, is
9 recommending that it go forward for
10 endorsement. The notes are always reflected
11 when that goes forward, so that both people
12 will see the vote and they will also see the
13 concerns that were raised, including the
14 recommendation. So I think that's good.
15 MS. McELVEEN: Do you want to vote
16 on that recommendation?
17 CO-CHAIR HOMER: I don't think we
18 need to. Okay. Well, congratulations. This
19 is good. We did four. We closed it. The
20 first are always the hardest.
21 MS. McELVEEN: They are.
22 CO-CHAIR HOMER: So, Nicole,

1 should we move into the clinical measures or
2 take a break? How do you want to proceed?
3 MS. McELVEEN: Do people need a
4 break? Does anyone feel like they need a
5 break? Okay.
6 CO-CHAIR HOMER: I would propose a
7 five minute break.
8 MS. McELVEEN: Okay. We can take
9 a five minute break.
10 (Whereupon, the above-entitled
11 matter went off the record at 10:24 a.m. and
12 resumed at 10:35 a.m.)
13 CO-CHAIR HOMER: Well, why don't
14 we reconvene? Thank you for allowing me to
15 replenish my coffee cup. I do, well we all
16 live on caffeine.
17 So now, we are going to move from
18 the population measures to some of the more
19 clinically oriented measures. And the first
20 group is the clinically, what is called, the
21 clinically-based measures. So these are the
22 ones that were -- whoops, am I --

1 MS. McELVEEN: That's 27, 28 and
2 29.
3 CO-CHAIR HOMER: 27, 28, 29,
4 right?
5 MS. McELVEEN: Yes, that's the old
6 agenda.
7 CO-CHAIR HOMER: Oh, I have the
8 wrong agenda in front of me.
9 MS. McELVEEN: Sorry.
10 CO-CHAIR HOMER: I'm sorry.
11 MS. McELVEEN: My apologies. I
12 copied the wrong agenda this morning. The
13 first set of measures will be Group 2. It's
14 the Questionnaire Survey Measures.
15 Does everyone have a copy of the
16 newer agenda, updated?
17 CO-CHAIR WEISS: No, it's not on--
18 MS. McELVEEN: It's not on the
19 flash drive.
20 CO-CHAIR WEISS: It's right here.
21 MS. McELVEEN: Ashley, do you have
22 more hard copies?

1 MS. MORSELL: The ones we handed
2 out are blank.
3 MS. McELVEEN: It was the wrong
4 one. You can use that.
5 CO-CHAIR HOMER: That's still the
6 wrong one.
7 MS. McELVEEN: Yes, sorry. That's
8 my copy. You can use that.
9 CO-CHAIR HOMER: So we are now
10 going to the group -- I stand corrected, or I
11 sit corrected. It's Measure 034, which is the
12 National Survey of Children with Special
13 Health Care Needs 2005/2006 and the quality
14 measure component thereof.
15 Do we have the steward on the
16 phone?
17 MS. McELVEEN: Do we have anyone?
18 CO-CHAIR HOMER: That would be
19 Christy.
20 MS. McELVEEN: Yes.
21 CO-CHAIR HOMER: Do we have anyone
22 from CAHMI on the line?

1 CO-CHAIR HOMER: Marlene, are you
2 still there?
3 MEMBER MILLER: I'm here.
4 CO-CHAIR HOMER: Oh, good.
5 MS. McELVEEN: Any other measure
6 developers on the line? They have a correct
7 copy of the agenda, so they are aware. So we
8 will just go ahead and get started.
9 CO-CHAIR HOMER: Okay.
10 MS. McELVEEN: We will just go
11 ahead and get started with that, this first
12 group of measures. Again, this is Group 2.
13 PARTICIPANT: So it's 34?
14 MS. McELVEEN: So we are starting
15 with Measure 34. The reviewers were Bonnie
16 Zima, Jane Perkins, Nancy Fisher and Ellen
17 Schwalenstocker. And just as a separate note,
18 this first measure that we are looking at,
19 Measure 34, the National Survey of Children
20 with Special Health Care Needs Quality
21 Measures, within that particular larger
22 survey, there are individual, smaller measures

1 that are comprised of the larger survey
2 measure.
3 Two of those were also submitted
4 individually. And those were 35 and 37. So
5 just so you know as we are reviewing them,
6 when we get to those, 35 and 37, those
7 measures are actually a component of that
8 larger survey measure.
9 Projected on the screen is
10 feedback from the reviewers, their ratings of
11 the sub-criteria and also any comments or
12 concerns that were raised while they were
13 reviewing this particular measure. And this
14 information is also on your thumb drive.
15 Let me just quickly read a
16 description of the measure just to introduce
17 it a little bit. This is the National Survey
18 of Children with Special Health Needs. It is
19 a population-based survey designed to assess
20 how well the nation and each state meet the
21 Maternal and Child Health Bureau's strategic
22 plan goals and the national performance

1 measures specifically for children with
2 special health care needs.
3 The questions address a variety of
4 physical, emotional and behavioral health
5 indicators and measures of children's health
6 experience with the health care system and ten
7 of these measures are directly focused on
8 children's health care quality.
9 Do we have any of the assigned
10 reviewers who want to take a first stab at
11 kind of reviewing their initial evaluation of
12 the measure?
13 CO-CHAIR HOMER: Thank you, Ellen.
14 MEMBER SCHWALENSTOCKER: I have
15 not had a chance to sort of synthesize the
16 comments, so these are just sort of my
17 perceptions.
18 But I really had trouble with this
19 one, because I was trying to figure out how to
20 evaluate the overall instrument. You know, it
21 seemed to me, and I honestly haven't gotten to
22 look at the details for the subgroups 3 and 4,

1 but it seemed to me throughout, a number of
2 individual measures were pulled out of this,
3 so I had trouble, you know, sort of figuring
4 out what kind of context to put this in.
5 But I did have a couple of bigger
6 concerns with the survey itself. One is, I
7 would really like to know more about what we
8 know about the response rate and potential for
9 response bias, because it is probably one of
10 the longest surveys I have ever seen and a
11 number of quite sensitive questions.
12 So I wondered about the dropout
13 rate and then I also wondered about how
14 accurately we know that the family member can
15 respond to some of these questions. Like how
16 many hours did you spend caring for your child
17 over X time period.
18 So I had difficulty trying to
19 figure out how to assess the questionnaire
20 overall and found myself wanting a lot more
21 information over, you know, just what we know
22 about response rate and accuracy of reports.

1 MEMBER FISHER: You make me feel
2 so much better. I agree with her that I
3 thought the survey was quite long and wondered
4 if somebody was even using it, whether you
5 could get enough people to participate.
6 But I felt that the survey was not
7 what was needed here. What we needed was
8 specific measures. This is a good way to, if
9 you are using a survey, to gather information.
10 And then after you gather the information,
11 because of the information you have in the
12 survey, you may put out some measures you want
13 from your analysis of the survey.
14 So I didn't think that that really
15 fit in with what we were doing.
16 MEMBER JENKINS: Is it being put
17 forward as a population-based measure or
18 what's the unit of analysis?
19 MEMBER SCHWALENSTOCKER: Charlie,
20 if I could add one more thing? I mean, it
21 looks to me like it is pretty widely used. So
22 I guess I would want --

1 CO-CHAIR HOMER: This is --
2 MEMBER SCHWALENSTOCKER: -- more
3 information about how it has been used and how
4 useful it is. And I just couldn't assess that
5 from the materials.
6 CO-CHAIR HOMER: Yes. So I'm
7 concerned that Christy Bethell, the developer,
8 isn't on the phone, because this is extremely
9 widely used. I mean, it is, for example, what
10 every state at the population health level for
11 the State Title V Programs, this is how they
12 are assessed, is they are assessed on what
13 proportion of children have a medical home?
14 What proportion of children have access to
15 health insurance? What proportion -- you
16 know, how satisfied are parents with the
17 services they receive?
18 Those are all derived from this
19 measure.
20 CO-CHAIR WEISS: Let me add that
21 this survey is an outgrowth of legislation
22 that was enacted in the late 1980s that

1 imposed upon Title V Programs for the first
2 time a requirement that they obtain
3 information on patient care that is delivered
4 through their program.
5 And the way it is structured is
6 that there are a series of data elements that
7 they look at and states have certain items to
8 which they must respond and others that are
9 available to them on a voluntary basis.
10 So it is widely used. The data is
11 being collected. How well or, you know, how
12 consistently across the country is open to
13 question. But the data is there and there is
14 legislation that lies behind that requires it
15 at this point.
16 Now, it may be -- I mean, this is
17 an old instrument and an old directive and it
18 may be that this is one of the areas that we
19 should point to for HHS to take a fresh look.
20 MEMBER FISHER: You know, but
21 going along with what you said it is being
22 used, then to me, like you said, there is

1 certain things you have to answer and you have
2 to do. What I'm saying is you have this
3 instrument. It is being used. So you look at
4 it and you say okay and you look across the
5 country and you see that children with special
6 health care needs, they don't have a medical
7 home.
8 Okay. Then, to me, you put a
9 measure. So you find out what is going on
10 with the kids, why don't they have a home?
11 And so, to me, it's gathering a lot of
12 information, but, in itself, it has got a lot
13 of measures in it.
14 CO-CHAIR HOMER: Right.
15 MEMBER FISHER: And it's just too
16 big, too broad, but it's something that I
17 think that we can use, because we have
18 information. To me, it's the information for
19 gaps or what you want to make improvement on
20 and what you want to then go down and be
21 specific and hone in on.
22 So that's why I said I didn't

1 think it fit in with what we were doing. And
2 they did submit the other measures, see, and
3 that makes sense to me.
4 MEMBER LIEBERTHAL: I had the
5 question, because this applies to Group 3 also
6 that I was on, is why did they submit the
7 whole survey as a measure and then pick out a
8 couple of the questions also as measures?
9 It would appear to me that each of
10 these questions should be evaluated on their
11 own merits, because some of them may be valid
12 for quality measures, whereas others may have
13 problems that would make them not acceptable.
14 So I don't know if we have the
15 option of separating them all out or just take
16 the two that they chose to separate out.
17 CO-CHAIR HOMER: Kathy?
18 MEMBER JENKINS: Allan, I agree in
19 terms of this being exactly the issue in one
20 of the measures in Group 3, but I don't think
21 it is the whole survey.
22 CO-CHAIR HOMER: No.

1 MEMBER JENKINS: I think that they
2 have chosen 15 individual items, which they
3 regard as the quality measures on the entire
4 survey. They are though, to your point,
5 proposing all 15 as a group. And when I tried
6 to do that on the other survey, I had the
7 exact same issue where I had to -- I couldn't
8 really consider them as a group, because my
9 answer depended very much on which of the 15
10 or however many it was in the other survey we
11 were referring to.
12 CO-CHAIR HOMER: So let me ask NQF
13 staff. I mean, another survey which is
14 broadly endorsed by NQF is the CAHPS Survey.
15 The same concept though is that really what
16 you use on the CAHPS Survey is not CAHPS, but
17 you use the variety of domains and domain
18 scores and things like that.
19 But if I understand correctly,
20 CAHPS itself is endorsed rather than the
21 specific domains and reports that come out of
22 it. Tell us how that was handled.

1 DR. WINKLER: Okay.
2 CO-CHAIR HOMER: Because I would
3 think this is a pretty similar kind of issue.
4 DR. WINKLER: Yes, yes. The
5 problem with what you are saying, Charlie, is
6 the two don't separate very readily, because
7 the instrument is the tool, the data gathering
8 tool. And you can't use an alternate tool to
9 create the summary results of the CAHPS
10 Survey, and there are several of them.
11 So the measure is actually those
12 results that are reported, but the tool is an,
13 you know, inextricable part of the measure in
14 how to collect the data to create those
15 summary results that are the things that are
16 posted and published and all of that.
17 So similarly, I think, you can
18 look at these as you have a tool versus you
19 have the information that you would report
20 about whatever as more of the measures. But
21 the two have to be related, because it's not
22 as if you can use another instrument or some

1 alternative data collection method to get the
2 information to create those measures.
3 MEMBER FISHER: Is the idea to
4 endorse a tool, so that everything is
5 consistent? I mean, you know, so that
6 somebody else doesn't come up with another
7 tool?
8 DR. WINKLER: Right. I think that
9 heretofore what NQF has done is endorsed tools
10 sort of as part of measures that are well-
11 defined because we want standard measures that
12 can be used to allow the comparability.
13 When it comes to survey tools, you
14 pretty much end up endorsing the tool, but
15 that isn't our primary focus to endorse the
16 tool. It is to endorse the measures that are
17 derived from that data collection methodology.
18 Okay.
19 MEMBER FISHER: Well, I feel like
20 I sort of screwed up, because I should have
21 looked at each one of the individual measures
22 for the endorsement.

1 DR. WINKLER: You know, the
2 question I would ask on this one is using the
3 tool as presented here with the multiple
4 parts, is there a summary result that comes
5 from it that is the measure?
6 I know, what would you publicly
7 report from this?
8 MEMBER JENKINS: Well, I think
9 that's what they have tried to do. They did
10 it in two ways. For certain individual
11 components, they created what they are
12 considering to be a summary. And in this
13 case, we have to say outcome measure.
14 The one that we are working on
15 here though, there is no summary measure and
16 it does appear as if there is 15, some of
17 which on this instrument and the other one, I
18 regard as structure process and some I regard
19 as outcomes and some probably could be either.
20 So we have that additional problem.
21 MEMBER SCHWALENSTOCKER: You know,
22 that was actually another point of confusion

1 for me in that they talk about 15, but then
2 listed are actually 22 measures. So I wasn't
3 sure. I just wasn't sure how to assess this
4 tool.
5 MEMBER JENKINS: I personally
6 would take the position that we cannot endorse
7 all 15 or 22 or however many it is for Group
8 3 all as one, that we can only endorse them at
9 the individual level, that's my personal
10 recommendation.
11 MEMBER FISHER: I was going to say
12 the same thing that we would have to take
13 them, you know, at another session or
14 something, divide them up and look at them and
15 endorse certain ones for the survey if that's
16 what they want.
17 DR. WINKLER: These have been
18 submitted to us as those individual measures,
19 however many there are, as well as the tool.
20 And it is unfortunate. Are we expecting
21 Christy so she can answer the question of why
22 the tool is also submitted as well as the

1 measures derived from it? I think that's an
2 important issue to resolve.
3 MEMBER FISHER: All of the 22
4 measures have been submitted.
5 MEMBER JENKINS: It isn't
6 submitted. It's only for -- if you look at
7 the numerator, that's where you can figure it
8 out.
9 MEMBER FISHER: Oh.
10 MEMBER JENKINS: So I'm looking on
11 the Numerators 2-A, 2-1, I think. Well,
12 that's the algorithm. Numerators comprise,
13 that's where you can figure out what their
14 measures are. And to me, it looks like a
15 group of measures. It doesn't look -- it
16 looks like 15, but maybe if you counted them
17 it's 22.
18 CO-CHAIR HOMER: Right.
19 CO-CHAIR WEISS: I think this is a
20 different population. 22 of all children were
21 served by time, whereas children with special
22 health needs in the population here.

1 CO-CHAIR HOMER: No, you turned it
2 off.
3 CO-CHAIR WEISS: That's where the
4 15 comes.
5 MEMBER JENKINS: That's true in
6 the other survey, but this is the special
7 health care needs survey.
8 CO-CHAIR HOMER: Yes, this is the
9 National Survey. And then it's this --
10 MEMBER JENKINS: The other one,
11 there is that issue where it is stratified by
12 special health care needs versus not.
13 CO-CHAIR WEISS: Right. 33 goes
14 to the issue of all 22?
15 MEMBER FISHER: Is that 33?
16 CO-CHAIR HOMER: 33 is Group 3.
17 DR. WINKLER: We need Christy,
18 right?
19 CO-CHAIR HOMER: Yes. I think the
20 short answer is we need Christy. I mean,
21 these are 15 more or less performance measures
22 for children with special health care needs

1 based on items from the National Survey for
2 Children.
3 MEMBER FISHER: Right.
4 MEMBER JENKINS: Right.
5 CO-CHAIR HOMER: So there is no
6 way to calculate these without the National
7 Survey.
8 DR. WINKLER: Right.
9 CO-CHAIR HOMER: But I think what
10 I'm hearing from the group is (A) a desire to
11 have more information on the psychometric
12 properties of the instrument so response
13 rates, et cetera, et cetera, which I suspect
14 will be readily available.
15 And then the second is people
16 really want to know more specifics about each
17 of these items or each of these. Some of
18 these measures are from single items. Most of
19 them are actually composites from several
20 items together. And that's what you would
21 like to know.
22 MEMBER ZIMA: There is also kind

1 of a prematurity to thinking about this as an
2 indicator quality, I think. And maybe this is
3 something to put on GAP. There is also a
4 heterogeneity around CSHCN definition. And so
5 it's sort of you have sort of heterogeneity in
6 the numerator whether it is type of service,
7 unmet need or need for service.
8 And then you have this
9 heterogeneous group and I would like to
10 propose that, you know, as we think about
11 future steps, you know, perhaps we need to be
12 also teasing out what this CSHCN Group really
13 is.
14 CO-CHAIR HOMER: But I guess I
15 would contend we could certainly discuss that.
16 I would contend that this measure reflects 15
17 years of discussion and, basically, consensus
18 within the maternal child health community
19 around what comprises children with special
20 health care needs and this measure. The
21 screener was really designed to reflect that
22 consensus definition.

1 So for NQF to sort of deconstruct
2 that would be difficult.
3 MEMBER McINERNY: You don't want
4 to go there.
5 CO-CHAIR HOMER: Yes, I wouldn't
6 recommend it.
7 MEMBER FISHER: I agree with you
8 that there is some heterogeneity around it,
9 but it has been defined for the people that
10 are going out and they are looking at this for
11 like your Medicaid population and stuff as the
12 person who has done that.
13 So it has been defined. They have
14 a special thing for it, especially the people
15 that audit the Medicaid programs and for the
16 Balance Budget Act that was passed. They have
17 specific things that they put into a group.
18 It's still sort of a heterogeneous group, but
19 it's defined that way.
20 CO-CHAIR WEISS: But you are quite
21 right, Bonnie. It is a very broad definition.
22 CO-CHAIR HOMER: Okay, yes.

1 MEMBER JENKINS: I saw that issue
2 as affecting the actionability of the
3 findings.
4 DR. WINKLER: What I'm hearing
5 from everybody is this measure actually, you
6 can call it anything you want, but, is a
7 compound measure, so that a result from it
8 would give you 15 separate reports out.
9 CO-CHAIR HOMER: Right.
10 DR. WINKLER: But as a single
11 measure, all 15 would be required. And so
12 that would be the output. It's not a
13 composite measure, because those 15 aren't in
14 some way summed up or aggregated for a single.
15 So I don't know what you would call it, but it
16 has these multiple -- it's a multi-part
17 measure for sure.
18 And I think the question for the
19 Committee is starting to address the issues
20 that Kathy and Ellen and Nancy have brought up
21 is since you would be obligated to include all
22 of these parts if we were to endorse this

1 measure, is what you would want to do?
2 Do you have concerns about certain
3 parts of it versus others? Realizing that
4 there are other measures that are more singles
5 that they have also submitted using the same
6 tool.
7 CO-CHAIR HOMER: Tom?
8 MEMBER McINERNY: Yes. As I look
9 at these 15 measures, I think, all except
10 perhaps that last one are really process
11 measures.
12 DR. WINKLER: Yes.
13 MEMBER McINERNY: And it's only
14 the last one that says on that health care
15 needs that is an outcome measure, in my mind,
16 the rest are all, you know, do you have
17 insurance? Do you have a physician? Do you
18 get family-centered care?
19 CO-CHAIR HOMER: But --
20 MEMBER McINERNY: So those aren't
21 really outcomes.
22 CO-CHAIR HOMER: -- I would beg to

1 differ or, at least, suggest that they could
2 be viewed either way. Just like one could
3 say, for example, hospitalization for asthma
4 is a process really. It's not an outcome.
5 That is you are doing something to a patient.
6 Having a medical home can be
7 viewed as, I mean it can be viewed, as an
8 outcome. Having effective care coordination
9 can be viewed. I mean, those things we
10 included in our solicitation health processes
11 as potential outcomes.
12 So I think these are on the
13 border. These are -- again, we can challenge
14 this, the Maternal Child Health Bureau's
15 Division of Children with Special Health Care
16 Needs has six aims that they have articulated
17 through a public process for children with
18 special health care needs, that is that all
19 children should have -- all kids with special
20 health care needs should have insurance, that
21 they should have a medical home, that care be
22 accessible, you know, et cetera. And it

1 should be that care be culturally competent.
2 I'm forgetting two, because of my lack of
3 sleep.
4 But basically, those the Maternal
5 Child Health Bureau would consider, quote,
6 outcomes. This group, if you want, I mean we
7 can call them processes, but I think these are
8 on the fence between processes and outcomes.
9 MEMBER DOCHERTY: I think
10 especially for this population that they are
11 outcomes.
12 CO-CHAIR HOMER: Yes.
13 MEMBER DOCHERTY: They are
14 important outcomes.
15 CO-CHAIR HOMER: Okay. I guess I
16 think -- I hate to disrupt the process because
17 it looks like survey measures are very
18 substantial, I think we need the steward to
19 actually have a fair conversation around this
20 and just wonder if we can move to some other?
21 If we could sort of table some of this
22 conversation until we can get Dr. Bethell on

1 the phone and then come back to a broader
2 discussion of these? Is the Committee willing
3 to do that and staff okay with that?
4 DR. WINKLER: What do we know
5 about her availability?
6 MS. McELVEEN: She will call in.
7 We are expecting, obviously, for her to call
8 in. There are several staff Members that are
9 sort of staggering their time to call in to
10 try and be here available for us. So we are
11 trying to get in contact with them. We have
12 emailed them, so hopefully they will be
13 calling in shortly.
14 My suggestion was to move onto
15 Measure 43. The measure developer is here in
16 person, but I just saw him step out for a
17 second.
18 CO-CHAIR HOMER: But what usually
19 happens is we would have one of the reviewers,
20 right, discuss it and then round him up.
21 MS. McELVEEN: Absolutely. So
22 what we are going to do, Measure 43 is still

1 a part of Group 2. It is titled the Pediatric
2 Symptom Checklist. And I'm going to quickly
3 pull up the feedback from a few of the
4 reviewers who were able to provide us feedback
5 on the sub-criteria for this measure.
6 Let's see, all righty. And this
7 particular measure's description is a brief
8 parent report questionnaire that is used to
9 measure overall psychosocial functioning in
10 children from ages 4 to 16 years of age. It
11 was, it looks like, originally developed to
12 allow pediatricians and other health
13 professions to identify children with poor
14 overall functioning who are in need of further
15 evaluation or referrals.
16 In addition to the original 35
17 item parent report form, there are now other
18 validated forms and translations, it looks
19 like, of this particular survey.
20 I would like to just open it up to
21 Michael Murphy who is part of the Measure
22 Development Team, if he had any comments,

1 prior to the Committee discussing the measure
2 or just -- okay. So we will open it up to the
3 group for further discussion.
4 It looks like again this is, it
5 looks like, another survey questionnaire type
6 of measure. So I think it might be worth kind
7 of going through importance a little bit
8 first. It looks like the Committee is on the
9 fence in terms of this.
10 MEMBER JENKINS: Can I ask Michael
11 a question? If he could just explain why it
12 is an outcome measure, I think contextually
13 that would be really helpful to us.
14 DR. MURPHY: I think that --
15 CO-CHAIR HOMER: Just come up and
16 use the microphone, please.
17 MEMBER JENKINS: There is a seat
18 right up here, if you would like to come down.
19 I'm not so sure how you are defining the term
20 Health Outcome Steering Committee, so I think
21 we have been discussing a lot of issues around
22 that definition. So I just wanted to hear

1 your perspective about the checklist as an
2 outcome measure.
3 CO-CHAIR HOMER: So again, I think
4 in the context, if it was initially designed
5 as a screening test, so something that might
6 indicate there was a problem, now, it is being
7 proposed in the sense as an outcome measure
8 that is something that is really reflecting
9 that there is a problem as opposed to there is
10 an increased likelihood compared to baseline.
11 So I think to put a finer point on
12 it, can you talk a little bit more about your
13 level of confidence and the abnormal screening
14 on one or more dimensions of the PSC actually
15 as an outcome measure that would be important
16 to track on a population basis or to indicate
17 one population is more healthy or less healthy
18 than another population?
19 DR. MURPHY: You're speaking so
20 well, I think I should just have you keep
21 going, but actually it's a great question,
22 because it was designed as a screen, but

1 because it is used so much, it is being used
2 as an outcome measure.
3 So you know, we don't have any --
4 CO-CHAIR HOMER: Do you have any
5 evidence yet from the literature? I guess
6 this goes really to the validity more than the
7 importance character, but the validity that an
8 abnormal screen is associated? And can you
9 talk about the predictive value
10 positive/negative sensitivities, specificity,
11 you know, or conceptually, but something along
12 those lines that says your level of
13 confidence?
14 People are using it, but just
15 because people are using it, doesn't
16 necessarily mean it is the right thing to do.
17 So just talk a little more about the
18 scientific basis for that.
19 DR. MURPHY: Yes. So to go back
20 and forth, I read some of the comments, I
21 guess, from last night. Our confidence in it
22 as you and I discussed on the break, it's

1 being used in Massachusetts and, you know, we
2 have some data. One is a published study from
3 Cambridge 2009, a relatively large population
4 of about 1,000.
5 And then we have data from the
6 State of Massachusetts, which is, you know,
7 tens of thousands of cases that we have seen.
8 So in terms of its validity as something that
9 can pick up kids -- one of the reviewers asked
10 what's the evidence that positive screens lead
11 to referrals?
12 And so now, both in a sample of
13 1,000 Cambridge and in the State of
14 Massachusetts as a whole, we have data that
15 shows that positive screens are referred. So
16 in terms of the usefulness of it, I mean,
17 that's sidestepping the issue of validity.
18 So is that a good start or you
19 want more on the positive predictive validity?
20 CO-CHAIR HOMER: I mean, we need,
21 I guess, the threshold. Maybe we got out of -
22 - the threshold question is important and I

1 actually do see that some of the reviewers had
2 concerns about importance. That is can you
3 talk a little about, this should be a medium -
4 - from my perspective, this is a medium speed,
5 fast ball right down the middle of the plate.
6 It should be able to wallop this
7 one out there, but editorial judgment.
8 Can you talk a little about what
9 the evidence is that psychosocial issues are
10 broadly defined, significant problems in child
11 health and that this measure -- and that there
12 is a gap between current practice and what,
13 you know, is a desired practice? Because that
14 -- again, I'm seeing the scores on this are
15 partially and minimally, that is nobody felt
16 that at least the report that was submitted
17 clearly indicated that they were convinced
18 that this is a particular issue, psychosocial
19 problems, and the current practice is
20 inadequate to identify it.
21 DR. MURPHY: So yes, I thought --
22 I was surprised when I talked to Mike Jellinek

1 a little bit about it, you know, from our
2 point of view. And we think from National
3 Standards point of view, psychosocial problems
4 broadly defined are a hugely important issue.
5 So it's an aspect of medical care
6 for kids and for adults that is left out, has
7 traditionally been left out and there is tons
8 of, you know, high level legislation and
9 Committee recommendations that are being
10 included as a part of routine health care.
11 So anyway, so there is a large
12 literature and a long term of literature that
13 says psychosocial problems broadly defined are
14 very important, both for physical health and
15 for life outcomes.
16 CO-CHAIR HOMER: And the current
17 practice?
18 DR. MURPHY: Thank you. And the
19 current practice remains. You know, Tom
20 McInerny is here. He as a part of a study a
21 decade ago that looked at Jane Costello's data
22 from two decades earlier and Barbara

1 Starfield's evidence from three decades
2 earlier that psychosocial problems are
3 routinely under-identified and under-acted
4 upon.
5 So it's a continuing problem that
6 legislation has sought to address and the PSC
7 is a well-validated way to identify the
8 problems and now we seek to actually get more
9 referrals.
10 You know, some of the questions
11 you were asking before about sensitivity and
12 specificity and critic to validity, the data
13 is very strong, I think, that when a kid
14 screens positive with the PSC, they have a
15 psychosocial problem of some sort.
16 And we have actually done some
17 work over the past decade to drill down in
18 terms of which types of problems, you know,
19 the subscales show which types of problems.
20 MEMBER PERSAUD: I have a
21 question. Is there any correlation between
22 the checklist and school readiness? Is there

1 any information on that?
2 DR. MURPHY: In terms of tests,
3 academic standardized test scores and stuff?
4 MEMBER PERSAUD: Yes, predicting
5 bad or poor performance if you have a positive
6 screen and no intervention?
7 DR. MURPHY: You know, actually,
8 the country of Chile has implemented this on
9 a national scale, so we are getting tens of
10 thousands of cases from them and their
11 educational system is very much like the U.S.
12 system. So they have standardized academic
13 test scores in the fourth grade and they test
14 the kids in the first grade.
15 And the scores are highly
16 predictive. So we are working on a couple of
17 papers to show that a negative screen in the
18 first grade predicts a poor test performance
19 in the fourth grade.
20 CO-CHAIR HOMER: Not to be hard-
21 nosed, but do you actually have numbers you
22 could share? So typically on other committees

1 I have been on, people would submit
2 manuscripts and press and things like that, so
3 we could actually --
4 DR. MURPHY: We have a manuscript
5 that has been making the rounds of journals
6 being rejected, but we could send you a couple
7 different versions, but, basically, it talks
8 about the association between the PSC score
9 and the standardized test score. So I could
10 email that to the Members of the Committee.
11 It's not quite ready for prime time, but it's
12 readable and rejectable.
13 MEMBER PARTRIDGE: Charlie, can I
14 --
15 CO-CHAIR HOMER: Yes, please.
16 MEMBER PARTRIDGE: -- play a
17 player? I'm putting myself in a user role
18 here.
19 CO-CHAIR HOMER: Right.
20 MEMBER PARTRIDGE: I think I
21 understand what has happened in Massachusetts,
22 but I want you to confirm. This was,

1 obviously, designed as a screening tool, so
2 that it would help the pediatrician or the
3 clinic or whoever pick up the fact that this
4 is a child who seems to have some trouble.
5 CO-CHAIR HOMER: Right.
6 MEMBER PARTRIDGE: And what you
7 have discovered by its use, widespread use in
8 Massachusetts, is that, in fact, I, if I were
9 Judge Bigby, who is the Commissioner of Public
10 Health in Massachusetts, saw that there were
11 a lot of these positive scores, somehow that
12 you have been aggregating them so that the
13 information is trickling out from the practice
14 or the clinic, that I have a problem in my
15 community or in my state.
16 And over time, as I see the
17 referral rate tracking up, it looks like that
18 problem has been eased. Is that how you are
19 proposing we would think of this for an
20 outcome measure?
21 DR. MURPHY: I think that's a
22 great summary of the leap to, you know, system

1 use. Heretofore, it has been used again in
2 the study that Tom was part of, it was -- your
3 know, are mental health problems increasing in
4 the United States? So it was used as a part
5 of some national study.
6 You know, the regional differences
7 are there is pediatrician experience and
8 factors. So exactly those ways. So it has
9 certainly been used on a smaller scale way.
10 And now it is being used in a population-based
11 way to do the things you said.
12 You know, I haven't spoken about
13 the outcome measure issue. So we are using it
14 at Mass General as a pre-post quarterly
15 assessment. And so, you know, we finally got
16 it into our own system. And it works, you
17 know.
18 CO-CHAIR HOMER: When you say it
19 works, can you tell me a little more? Like --
20 DR. MURPHY: I'll try not to get
21 into much trouble here. Let me talk about
22 Brad Stein in Los Angeles first.

1 CO-CHAIR HOMER: Okay.
2 DR. MURPHY: So it has been used
3 in a number of studies as a pre-post measure
4 of, you know, children who are witnesses of
5 domestic violence and they have a PTSD
6 prevention curriculum in the Los Angeles
7 Public Schools and they pre-test them with the
8 PSC and they post-test them and they use that
9 as a pre-post measure.
10 So it has certainly been used in
11 half a dozen studies as a pre-post measure in
12 small samples.
13 At Mass General, we are just using
14 it as it's actually in the flow sheets, every
15 aspect of the flow sheets. We have blood
16 pressure and height and weight and we have a
17 psychosocial area now in the flow sheets of
18 the electronic medical record.
19 And so the idea is you want to see
20 the PSC scores going down over time. So they
21 do, but we are just -- you know, it's just in
22 the last six months that we have got them in

1 there and we're using it.

2 CO-CHAIR HOMER: Tom?

3 MEMBER McINERNY: Yes. And of

4 course, Massachusetts has what has been going

5 on now for two years, I think, to improve how

6 primary care physicians are able to access

7 mental health specialists to improve mental

8 health care for children.

9 So if one were doing the PSC

10 scores over time, if this program that was

11 implemented a couple of years ago was working,

12 you should expect to see the number of

13 positive PSC scores decrease, because there is

14 better mental health care. Is that another

15 way of saying this is a way to use this to

16 measure population health?

17 DR. MURPHY: Yes, it actually is.

18 And actually the data actually show that. We

19 have looked at two years of data, eight

20 quarters of data and the PSC positive rate has

21 gone down slightly from 13 percent to 12

22 percent or something like that.

1 You know, there is a sense that
2 with continued screening and referral, you can
3 see the rates go down a little bit.
4 MEMBER McINERNY: And
5 interestingly, this really could also be a
6 process measure in that one could say just as
7 we would expect primary care pediatricians to
8 be doing developmental screening at certain
9 ages, a lot of people say, Michael especially,
10 that primary care pediatricians should be
11 doing PSCs on a regular basis, maybe at every
12 well child evaluation and we could measure how
13 many pediatricians are doing that.
14 Just like we are trying to get
15 pediatricians to do BMI percentiles and see if
16 that is improving over time. But that's only
17 a process measure. It's not an outcome
18 measure. But it could be used in sort of both
19 ways.
20 CO-CHAIR HOMER: And so just
21 proceeding along, it sounds like -- are there
22 further questions about the impact gap

1 relation to outcomes or that section feels
2 like we have gotten some good information and
3 people seem comfortable with this as an
4 outcome measure?
5 So now, if we could -- I'm sorry?
6 DR. WINKLER: We probably need to
7 have the Committee vote on that.
8 MS. McELVEEN: Yes.
9 CO-CHAIR HOMER: Because that's a
10 threshold.
11 DR. WINKLER: Yes, it's a
12 threshold.
13 CO-CHAIR HOMER: Okay. So how do
14 you vote on this? Do you say simply vote for
15 those who feel it is --
16 DR. WINKLER: It's yes/no
17 criteria.
18 CO-CHAIR HOMER: Yes/no important
19 enough to -- important to measure? All those
20 who believe that the PSC indicates something
21 sufficiently important to measure?
22 DR. WINKLER: 12, 13. Marlene?

1 Marlene?

2 MEMBER MILLER: I vote yes.

3 DR. WINKLER: Okay. So that's 14.

4 I saw one hand who didn't vote. Nancy?

5 CO-CHAIR HOMER: It's like the

6 hand that didn't --

7 DR. WINKLER: All right. Vote

8 nos?

9 CO-CHAIR HOMER: Andy, no? One

10 no.

11 DR. WINKLER: One no, okay, that's

12 fine. Any abstentions? Okay.

13 CO-CHAIR HOMER: Okay. Let's talk

14 a little, if we can, about, if you could

15 scroll down to, the scientific acceptability

16 component, because that seems a little bit all

17 over the map. Not many voters.

18 So any comments or concerns about

19 specifications? Is it well-specified measure

20 of reliability, test, re-test and reiterated

21 reliability, validity, which I still didn't

22 really hear a clear answer for you actually on

1 sort of how well this relates to other
2 measures of behavioral and mental health. And
3 how well does it correlate with depression,
4 ADHD and OCDCL scores, other, you know,
5 indicators.
6 DR. MURPHY: If I can have that
7 fast --
8 CO-CHAIR HOMER: I'm now beyond my
9 competence.
10 DR. MURPHY: So reliability and
11 validity are not beyond my competence. So
12 given me that fast ball again, the reliability
13 and validity have been established in lots of
14 studies. They are comparable to anything
15 anybody gets of a brief measure, longer
16 measures like the Achenbach. Obviously, they
17 have slightly higher reliability and validity,
18 but not much.
19 In terms of -- there was just a
20 study by Bill Gardner and his associates that
21 had compared the PSC to a bunch of diagnosis-
22 specific measures like the CDI and RC Mass and

1 anxiety, depression, conduct, the ADD and have
2 found that the PSC subscales had similar
3 sensitivity and specificity to those longer
4 and well-accepted kind of gold standard tests.
5 So again, the PSC is kind of a
6 front end test that can screen for depression,
7 anxiety, attention and conduct problems, you
8 know, with reliability and validity that are
9 comparable to the other accepted standards.
10 CO-CHAIR HOMER: Okay.
11 DR. BETHELL: Hi, this is Christy.
12 CO-CHAIR HOMER: Oh, good.
13 DR. BETHELL: Sorry to join late.
14 If there are any questions, I just want to
15 make sure people know I was on the line.
16 CO-CHAIR HOMER: Christy, it's
17 great you are on the line. Christy, we
18 actually had started discussing the National
19 Survey and really deferred. There were so
20 many questions that we felt you were the best
21 person to answer, that we deferred
22 consideration.

1 We are currently reviewing the
2 PSC, Pediatric Symptom Checklist. And as soon
3 as we are finished with that, we will come
4 back and review. Go back to your measure.
5 So, please, do listen in. But now that we are
6 deep into this, we should finish consideration
7 of PSC and then come back to you.
8 DR. BETHELL: Great. Just to let
9 you know, I'll be in and out, so this is just
10 to -- you know, I'm not -- I'll be in and out.
11 I will do my best.
12 CO-CHAIR HOMER: Okay.
13 MEMBER McINERNY: You know, if you
14 look at 2C.1, that sample, there is some
15 validation description there. And that, to
16 me, looks pretty reasonable, as reasonable as
17 most of these kinds of screen tests can be.
18 And you know, I'm comfortable that the
19 validity is satisfactory.
20 MEMBER PERSAUD: I would also
21 comment that this score goes down to a pretty
22 low age, age 4. And I think at that age,

1 there is not or there aren't very many other
2 validated instruments.
3 CO-CHAIR HOMER: Yes.
4 MEMBER PERSAUD: And the PSC has
5 really, I think, been in the forefront for
6 that young age group. Actually, in my
7 practice, we use this as an outcome measure as
8 well. We have got an integrated mental health
9 program as a pilot. It's a large state
10 Medicaid grant in Texas.
11 And interestingly, we are
12 screening with a battery of other tests,
13 MCHAT, mental health tools, PEDs developmental
14 and then if we find something, it goes over to
15 a mental health therapist that then does a
16 number of screens.
17 This is one, but I'm virtually
18 certain in the research aspect of this
19 project, this is being used as one of the
20 outcome measures. And I think theoretically,
21 a part of it is if the parent thinks the child
22 isn't doing well, then that's an outcome.

1 They are not doing well.
2 DR. MURPHY: That's a really
3 important point. You know, it's a little bit
4 less sexy, because it's not an MCHAT or it's
5 not something, but, in fact, that single
6 domain of the parent not thinking the kids is
7 doing well is the kind of flag and it actually
8 can be driven down by a good support of
9 interventions of a broad -- you know, of many
10 different scores.
11 CO-CHAIR HOMER: So there is a
12 category in here that says meaningful
13 differences. So if this were to be used as a
14 performance measure, presumably, you would
15 want to be able to say Program A is different
16 than Program B or State A is different than
17 State B.
18 It says you hadn't explored that,
19 although you do have, you know, mean and
20 standard deviation measures. Have you really
21 not explored? In the various studies you have
22 done, have you looked at how this can be used

1 to compare performance across programs or
2 sites or things? I was surprised to see --
3 DR. MURPHY: You mean as an
4 outcome measure?
5 CO-CHAIR HOMER: Yes, yes.
6 DR. MURPHY: You know, you're
7 looking at the PSC Research Team.
8 CO-CHAIR HOMER: Okay.
9 DR. MURPHY: I'll give you that.
10 I took a Greyhound bus down here. We don't
11 have drug company funding. So, you know, we
12 do --
13 CO-CHAIR HOMER: I hope the Bolt
14 bus, you know.
15 DR. MURPHY: Yes, right.
16 CO-CHAIR HOMER: It's a little
17 better.
18 DR. MURPHY: Right. Anyway so,
19 you know, there are whole areas of this that
20 we haven't explored. You know, when Chile
21 starts to use it, we sort of shift our
22 attention to working with them and the

1 standardized test scores. So some of these
2 population-based things are really new to me
3 and I have very little familiarity with some
4 of the concepts.
5 CO-CHAIR HOMER: Okay.
6 MEMBER JENKINS: Wouldn't the
7 proposed use of this quality though in that
8 you are using it to evaluate an intervention?
9 It could be the interventions Donna is talking
10 about or within your clinic.
11 CO-CHAIR HOMER: Yes, please.
12 DR. WINKLER: One question. I'm
13 just looking at the information as submitted.
14 The way the numerator is stated, it just
15 describes the survey.
16 DR. MURPHY: Yes.
17 DR. WINKLER: So I'm not sure, how
18 do I count that numerator?
19 DR. MURPHY: How do you score it?
20 DR. WINKLER: For this measure and
21 then the denominator is, you know, all
22 children, I guess, and I'm assuming so --

1 DR. MURPHY: Yes, that's --
2 DR. WINKLER: -- all children in a
3 population, I assume, are eligible. So is
4 this the result, the percentage of children
5 for whom their parents filled out a survey or
6 is it the percent of children for whom -- that
7 had the survey done and it was abnormal or
8 normal or something?
9 This is what I'm unclear about.
10 And I don't find the --
11 DR. MURPHY: I agree.
12 DR. WINKLER: -- specifications to
13 be particularly precise. I can certainly see
14 where from this tool, using this tool, which
15 seems to be a well-validated at the individual
16 patient level and has a lot of support, but
17 using it to understand more about the quality
18 of care delivered of pre- and post- could be
19 another type of specification, but that isn't
20 what is given to us.
21 So I'm trying to get a handle on
22 what you are proposing is the exact

1 specification. What is it we are going to
2 compare from, you know, about providers? What
3 information about the quality of care do we
4 hope to obtain from this measure?
5 DR. MURPHY: You know, I think
6 it's a great question. And I think one
7 problem comes in on two different. I think
8 you said yourself, you know, the individual
9 case level is one. On the macro level, one of
10 the things that is hard to put into words is
11 that just whether -- I think Tom said this.
12 Whether a screen was given, you
13 know, in pediatrics. You know, the reason it
14 has been pushed nationally is that there is a
15 requirement to use standardized tools to
16 screen for psychosocial problems in
17 pediatrics.
18 CO-CHAIR HOMER: Sure.
19 DR. MURPHY: So yes, no. Was the
20 screening given? What Massachusetts does is
21 the bill. They have actually tied it to a
22 billing mechanism, a billing code. You know,

1 did they -- they gave the screen. They billed
2 for it. And we know what happened.
3 So at that level, I think, we have
4 done a lot more or we're doing a lot more.
5 CO-CHAIR HOMER: But you are
6 proposing this as an outcome measure. So as
7 an outcome measure, I mean, as you heard
8 earlier in conversation, we will have
9 opportunity as a Committee to review process
10 measures and this same set could be a very
11 good one.
12 But you are proposing it also as
13 an outcome measure. So how would -- what
14 would the -- you know, what would that number
15 be?
16 DR. MURPHY: Well, again, I think
17 as Tom said, I mean, one idea is the PSC
18 positive rate going down.
19 CO-CHAIR HOMER: So I'm going to
20 be like --
21 DR. MURPHY: The mean is going
22 down.

1 CO-CHAIR HOMER: I'm going to be a
2 little obnoxious. For us to approve it, we
3 have to actually have specification. So it
4 has to be different than we could consider.
5 It actually has to be the numerator is either
6 proportion positive, you know, number of
7 children who are positive and positive is
8 above the cutoff of yada, yada or the mean
9 score, you know.
10 But we actually have to have like
11 written out specifications of numerators and
12 denominators, so that if Colorado wants to
13 apply it, they will apply it in the same way
14 that Massachusetts applies it. So I mean, I
15 think we are just at the limit of our -- we
16 know that mean scores go down.
17 You know, at Mass General we got
18 in the treatment plan updates that we did.
19 Did the PSC score go down one point in the
20 last quarter? So is that the gold standard
21 number? I don't know, but that's what we are
22 -- so we are just starting to do that.

1 So we know that mean scores go
2 down. So Marina's was resubmitted as a
3 process. I guess I'm -- my quick take jumping
4 quickly to my global judgment is not quite
5 ready, that is the concept is totally right.
6 We're really excited about the measure, but
7 you haven't presented sufficient
8 specifications for us to make a judgment about
9 whether it is actually a performance measure
10 or not that can be used.
11 But that's my quick basis, because
12 there aren't specifications. That might be
13 jumping the gun.
14 MEMBER JENKINS: Well, I was going
15 to say that this is all why I asked my first
16 question.
17 CO-CHAIR HOMER: Yes.
18 MEMBER JENKINS: And I guess what
19 I am hearing is that now that we have
20 clarified the question, you may be able to
21 recast this as an outcome measure. Perhaps
22 not for the full endorsement, but that time

1 limited where you have 12 months to finish up
2 and fill in the holes of test, retest or
3 whatever is left.
4 I'm thinking it is possible that,
5 Charlie, it's not there, it's just not crafted
6 that way. Obviously, the use of it as a
7 process measure is easier and I would totally
8 suggest we put that forward to Part B of this
9 discussion.
10 CO-CHAIR HOMER: Yes.
11 MEMBER JENKINS: Because as a
12 process measure, it's easier.
13 CO-CHAIR HOMER: It's easier, yes.
14 MS. BOSSLEY: This is Heidi. I
15 mean, you can put that as a condition with
16 your recommendation and they can bring back
17 something and you will look at it again. So
18 this isn't the last time you could see it. We
19 could ask for a little bit more recrafting, a
20 little more rework and bring it back to you.
21 If again, you don't feel that it is quite
22 ready, then you can say that or you can say

1 it's time limited or whatever, all of that.
2 But it sounds like you would like
3 maybe possibly to entertain looking at this
4 again, so we can ask Dr. Murphy to go back and
5 do a little reworking on it, if you would
6 like.
7 CO-CHAIR HOMER: Yes, I was just
8 not seeing another meeting as an outcomes
9 meeting.
10 MS. BOSSLEY: We will give you a
11 call, if you need it.
12 CO-CHAIR HOMER: Okay.
13 MS. BOSSLEY: We won't give you a
14 meeting.
15 CO-CHAIR HOMER: So that's very
16 helpful. So I think actually can I move us
17 almost towards our vote on this or a
18 recommendation?
19 MS. McELVEEN: That's fine.
20 CO-CHAIR HOMER: Which is -- and
21 what I think I hear in the recommendation is
22 that, Michael that you have come back, you

1 have revised this measure and come back with
2 more detailed specifications for how this
3 could be used as an outcome measure.
4 I would suggest that rather than
5 approving with a conditional approval, because
6 in part, NQF is sort of trying to move away
7 from these conditional approvals.
8 MS. BOSSLEY: But I mean, I think
9 what you can do is table it, the discussion
10 for now.
11 CO-CHAIR HOMER: Yes, exactly.
12 MS. BOSSLEY: Yes.
13 CO-CHAIR HOMER: Table it, but,
14 please, come back with more detailed
15 specifications of how this could be used as an
16 outcome measure.
17 MEMBER FISHER: Could I ask a
18 question?
19 CO-CHAIR HOMER: Please.
20 MEMBER FISHER: In the usability -
21 -
22 COURT REPORTER: Can you turn your

1 mike on, please?
2 MEMBER FISHER: Oh, sorry. In the
3 usability, it says data has been reported to
4 a court monitor, so are a matter of public
5 record, but not yet published.
6 CO-CHAIR HOMER: I hear you.
7 MEMBER FISHER: So you use this
8 data and then you give it to the --
9 CO-CHAIR HOMER: Well, in
10 Massachusetts there is a legal settlement
11 called the Rosie D case.
12 MEMBER FISHER: Oh, okay.
13 CO-CHAIR HOMER: Which the state
14 was sued for providing inadequate mental
15 health to children. And as part of the
16 consent agreement --
17 MEMBER FISHER: Yes.
18 CO-CHAIR HOMER: -- this is part
19 of the consent agreement.
20 MEMBER FISHER: Okay.
21 CO-CHAIR HOMER: Which is that
22 every pediatrician has to screen. The

1 agreement was that every pediatrician has to
2 screen for mental health. It turns out that
3 they selected the PSC as one of the
4 instruments.
5 MEMBER FISHER: Oh, okay.
6 CO-CHAIR HOMER: So it's under a
7 court order.
8 MEMBER FISHER: Okay. Thank you.
9 CO-CHAIR HOMER: But more as a
10 process measure that they screen and that's
11 how much they improved.
12 MEMBER FISHER: Thank you.
13 CO-CHAIR HOMER: We're very
14 provincial in Massachusetts. We think
15 everybody does everything like us.
16 MS. McELVEEN: I just wanted to
17 clarify. Are there any other conditions that
18 you think would be important to be included to
19 find feedback for the developer? I know
20 Charlie specified it pretty clearly, but I
21 just want to make sure everyone --
22 MEMBER SCHWALENSTOCKER: I think

1 it would be helpful, and certainly there has
2 been some discussion around there, if you do
3 have data about, you know, what you have found
4 in terms of significant differences pre- and
5 post-, I think, that would be really helpful.
6 Recognizing it is early in its use for that.
7 DR. MURPHY: Clearly, we have to
8 go to school and get people that know how to
9 do this and look at our data.
10 MEMBER ZIMA: Well, I also would
11 like to think more about this discussion when
12 we talk about future steps, because this is
13 kind of the state of the art. And I think
14 what would be really interesting is, you have
15 such a heterogeneous symptoms, you know, and
16 some functioning and it is a little like the
17 CIS as well.
18 DR. MURPHY: Yes.
19 MEMBER ZIMA: You know, and so
20 what would be very interesting is the Columbia
21 Impairment Scale, which is a 13 item developed
22 by Columbia, and it too kind of combines

1 symptoms and function together.
2 And so it could be very
3 interesting like with your Chile population,
4 like where you have an adequate sample size
5 that we can maybe begin to tease out, you
6 know, the different domains within this.
7 Because I think eventually we have got to get
8 to the point where we are going to be matching
9 symptoms to recommended treatment. And we are
10 not there yet.
11 But I think that's something
12 perhaps again we should say best wishes, good
13 luck, good cause and how can we continue this
14 discussion as we think about what the future
15 steps should be around developing quality
16 measures for child mental health.
17 DR. MURPHY: Yes, that's a great
18 question. I mean, that's exactly the work we
19 are doing now looking at items and clusters
20 and what changes with intervention. Yes.
21 CO-CHAIR HOMER: So, general
22 agreement that we can table this with strong

1 encouragement to come back with additional
2 specifications? Terrific. Thank you. Again,
3 wonderful conversation.
4 So, Christy, are you still on the
5 line? I'm sorry, was that a yes? I couldn't
6 hear. Christy Bethell?
7 DR. BETHELL: Okay. You know, I
8 got cut off. Actually, believe it or not, it
9 took me about a half hour to get on the call
10 this morning.
11 CO-CHAIR HOMER: Oh.
12 DR. BETHELL: I kept getting on
13 and off and I just got off and I'm back on
14 again.
15 CO-CHAIR HOMER: Okay. So while
16 we have you, and I apologize on behalf of our
17 Committee for hassles you had in joining the
18 call.
19 DR. BETHELL: Yes.
20 CO-CHAIR HOMER: We had started a
21 conversation about Measure 34, which is what
22 we are calling Measure 34, the National Survey

1 of Children with Special Health Care Needs
2 Quality Measures, which included 15 specific
3 quality measures under the broad rubric of the
4 survey.
5 There were some initial questions,
6 which were just about survey methodology, you
7 know, response mechanism completion rate, you
8 know, response rate, completion rate.
9 DR. BETHELL: Yes.
10 CO-CHAIR HOMER: And I just
11 wondered if you could maybe quickly comment on
12 those first?
13 DR. BETHELL: Yes.
14 CO-CHAIR HOMER: And --
15 DR. BETHELL: And just as a
16 caveat, I mean, obviously, with the time that
17 we had, there is only so much you can provide.
18 But also so you know, there are incredibly in
19 depth, hundreds of pages, manual on sampling
20 and data collection and scoring of everything
21 that you see.
22 So it was a little but unclear

1 what to provide, so maybe we can, you know,
2 see what we can do now and then just know
3 there is more. So we want to serve it up as
4 it is needed or wanted and in a form that you
5 can -- that you want to have it in, which is,
6 of course, always a challenge.
7 The National Survey of Children
8 with Special Health Care Needs is a rate and
9 digit style survey feeding off of the sampling
10 frame for the National Immunization Survey.
11 And it is done in a way that yields
12 representative samples at the state and
13 national level.
14 And then the reading is done to
15 account -- have that be -- all the estimates
16 be representative of children living in each
17 state and the nation and also adjusting for
18 non-response to bias, which is mostly people
19 without telephones, and after being called 20
20 times, so there is a lot of detailed
21 information about response rate.
22 But depending on how you score it,

1 and there are different ways people score
2 response rate. It is anywhere from 58 to 61,
3 I think, percent.
4 CO-CHAIR HOMER: Which again, I
5 think, in the current year is a pretty high
6 response rate. So --
7 DR. BETHELL: Yes, but not only
8 that, there is a lot of adjustments made and
9 there has been a lot of analyses done to see
10 whether or not we are really missing groups of
11 people who don't have phones or who have only
12 cell phones. And this is an ongoing
13 discussion with a lot of energy being put in
14 to try and optimize the sample and otherwise
15 adjust on the back end for non-response.
16 CO-CHAIR HOMER: That's --
17 DR. BETHELL: There's a lot more
18 to say about that though, so that's a short
19 answer.
20 CO-CHAIR HOMER: I think that's
21 very helpful. Nancy, you, in particular,
22 raised questions about the sampling issues

1 response rate. Do you feel like your
2 responses are sufficiently addressed by that
3 or do you have any further questions around
4 sort of just the general survey methodology
5 and response rate and completion and that?
6 Because there were sort of broad questions
7 about that survey, since many people on the
8 Committee aren't familiar with its use.
9 Christy, there was also some
10 discussion and I know you could talk a long
11 time about this, but I think you can also
12 present it concisely, just about the screener
13 and the coherence of that and the issues
14 involved of having such a diverse set of
15 indicators for children with special health
16 care needs. And maybe a brief comment on the
17 rationale or the experience or how coherent
18 that set of children ends up being.
19 DR. BETHELL: Yes. Well, I mean,
20 if you know, Charlie, the three states on that
21 page, the definition of children's health
22 minus the average group, we're trying to

1 actually identify children who currently have
2 a special health care need, pretty much
3 defined as having an ongoing condition, at
4 least one, most of them have two or more. And
5 that that condition has resulted in above
6 routine need for health service of a type or
7 amount that is required by children generally.
8 And the screener again, I know,
9 Charlie, you will remember this, started out
10 with about 139 concepts defining consequences
11 and needs that children with current
12 conditions have and then through psychometric
13 testing and medical chart review and
14 administrative data reviews and comparison,
15 basically, identifies the five things that all
16 of them have, all of the children that we want
17 to include have.
18 So it's not a needs assessment of
19 everything children need. They share a lot in
20 common. They are distinctly different from
21 children who do not meet the screener in every
22 way that we have seen that pattern and we have

1 a million pieces of data and we always
2 reanalyze it.
3 Having said that, there is
4 diversity, even if you have a group of
5 children without and they follow along a
6 continuum of need and functioning and other
7 characteristics and consequences now, hereto,
8 no different than any single health condition.
9 And so what we have done is we have created a
10 way to stratify even the screener for how
11 children meet the screener to get some
12 complexity of need and complexity of severity.
13 And so there are several papers
14 published on that. There is a new paper out
15 by Adam Carle psychometrics independently
16 done. So we have a number of papers that we
17 can present about a variety of issues, whether
18 it is, you know, how the screener holds
19 together or who the kids are that are
20 represented, why they are different from
21 children who don't meet the screener, what
22 about missing cases that we would want to

1 include and so on.

2 So if you have more specific

3 questions, I could come right in and tell you.

4 But, yes, there is a range of children

5 represented, but all of them share the

6 experience of having an ongoing condition and

7 experiencing consequences of above routine

8 need or use of services.

9 CO-CHAIR HOMER: That's very

10 helpful and very concise and I appreciate

11 that, Christy. Bonnie or anyone else with

12 sort of questions about the screener per se

13 and the population that is then reflected in

14 the survey? And again, its importance or

15 relevance.

16 Okay. I think another set of

17 questions then and really where we were kind

18 of getting a little bollocksed up was the

19 actual quality indicators themselves.

20 Because one, I guess, one option

21 would have been to submit each of those as

22 separate measures, but you submitted them.

1 And again I know time was short and I'm not
2 sure what other conversations happened in the
3 background.
4 DR. BETHELL: It was really short.
5 At the time, when there is a lot of other
6 things, I think, I was at your meeting on
7 child measures when they were reviewed. The
8 college had come out a few days before, so it
9 was short.
10 But, basically, this is data that
11 your -- these measures that you see before you
12 already have data collected on them. And
13 there is plans to collect that data on a
14 routine basis to provide data at a population
15 level, which I understand is an NQF category
16 or unit of analysis, so they are valuable now
17 for purposes of looking at state and sub-state
18 data. Sub-state meaning sub-groups of
19 children within states.
20 So with that frame, it's not like
21 we are screening a measure to obtain any --
22 this is to collect data. This is data that

1 exists that could be enforced, if you will, by
2 NQF as measures that are meaningful for some
3 of the categories and unit analysis of
4 measurement that are priority.
5 So that's one reason to put it
6 together as a group.
7 Having said that, anybody could
8 take any single piece of it, like the medical
9 home module, obviously collecting the
10 variables that are needed and really just
11 collect the pieces and call it a measure.
12 Usually when people do a survey,
13 they try to get the biggest things for the
14 buck and being able to get a wide range of
15 information about health, health risks,
16 analytic variables and risk factors along with
17 quality measures at the same time.
18 So typically, people take a survey
19 and give you 15 different measures. Having
20 said that though, anybody could take it and
21 just collect the medical home module. You
22 know, with all the requisite variables that

1 are needed to stratify.

2 But that was the rationale for the

3 group also because we couldn't unbundle them.

4 We had a whole website that takes them one by

5 one and gets the numerator, the denominator

6 and we just submitted that. But I don't think

7 it has been reviewed. But I'm not sure what

8 the format you would want, because it would be

9 tenable for you, you know, to review.

10 CO-CHAIR HOMER: We are not sure

11 either, but so we are just working it out

12 today.

13 DR. BETHELL: But we have a lot,

14 and then I think that they do vary, the

15 measures that are within there, in terms of

16 where they come from. Obviously, the screener

17 was validated and adopted into the survey

18 before the survey was placed. The medical

19 home measure was a specific year long

20 measurement development and testing for more

21 than a year, but formally a year.

22 Some of the other ones are items

1 that come from other surveys. Some of them
2 were developed and tested cognitively and then
3 subsequently people have published on most of
4 the measures in a way that has been through
5 pretty extensive purity process where there
6 just had to be demonstration of IMs are all
7 that they say they are. And there is a number
8 of different ways to conduct the validity
9 question as well.
10 CO-CHAIR HOMER: Okay. Kathy?
11 MEMBER JENKINS: Could I just ask
12 my same question that I asked the last measure
13 developer related to this list in terms of the
14 use of this information as an outcome measure
15 as opposed to structural process? Because I'm
16 not going to what Dr. McInerny said before and
17 I agree with him. And to me, the list is
18 variable in that regard.
19 DR. BETHELL: Well, it wasn't
20 clear to me actually with the call to
21 measures. I agree with you. What the -- like
22 with the medical home, what if -- it just

1 wasn't clear to me what that would be
2 categorized as, if we were generous and
3 included things.
4 CO-CHAIR HOMER: In other words,
5 you think this is a mixture of process and
6 outcome measures?
7 MEMBER JENKINS: As an example,
8 the one that says proportion who are screened
9 early and continuously. I assume that since
10 you have put it forward, you are regarding
11 variation or cross-set as an outcome measure?
12 DR. BETHELL: You know, again, the
13 call for measures didn't make it clear to me
14 where you were. You know, there is a
15 continuum of what people think of as outcomes.
16 So if you are speaking health outcomes, then
17 there is a subset within there. And it's very
18 tricky to get at health outcomes, but there
19 are some that are in there like how much the
20 child is affected.
21 I don't have the list in front of
22 me, so if you could maybe call one out in

1 specific, I could address that.
2 MEMBER JENKINS: I guess my
3 general question is, have you developed any of
4 the evidence that the individual items are
5 linked to child health outcomes or predictive
6 of child health outcomes? In a formal way, as
7 opposed to just on the face of it.
8 DR. BETHELL: Right. Well, keep
9 in mind that the National Survey is, and this
10 would be true for state level, a cross-
11 sectional survey. And so the validation is
12 really internal to the sampling frame that is
13 there.
14 And, yes, there are all these
15 associations you would expect to show up that
16 children with certain levels of system
17 performance, if you will, whether it is
18 inadequate insurance or having a medical home,
19 vary as expected on the other more outcomes-
20 oriented frames, adjusting for all other
21 things that you might want to adjust for that
22 also might contribute to variations in those

1 outcomes.
2 So that kind of data does exist.
3 And then there are separate studies where
4 people have used pieces of the survey in
5 independent studies with independent data
6 collection where some of that also comes out.
7 So I think all of that together would be a
8 task, and I think the question was if there is
9 enough interest to justify moving forward with
10 that level of work.
11 CO-CHAIR HOMER: I think actually
12 we may need to go one-by-one to actually
13 answer some of those questions, if that's not
14 too painful, I mean.
15 DR. BETHELL: Yes, it's not too
16 painful, but it's an extensive process and
17 that's why I was not clear how we were going
18 to really proceed with this.
19 CO-CHAIR HOMER: No, but I was
20 even thinking as a Committee task right now.
21 I mean, I could say, for example, your first--
22 I appreciate you don't have the list in front

1 of you.

2 So the first one was the effect of

3 a child's conditions on their daily life. So

4 presumably, that's an outcome measure. That

5 is, there is some indicator of, again, I don't

6 know what the response categories are and what

7 that actually means to say, affect on their

8 daily life, but I'm sure that's something like

9 impaired or not impaired or interferes or

10 doesn't interfere or something along those

11 lines?

12 DR. BETHELL: You know, this may

13 sound really wild, but because the Committee

14 is needing this information, it actually is

15 all up on our website. Like if you went to

16 the website and clicked on that list over

17 there, there is a box that pops up that is

18 numerator/ denominator, if you want to see the

19 exact questions that are in it, you just click

20 and they come up.

21 And I am not sure how to be more

22 efficient than that without giving you a

1 binder that is like 3 inches thick. You know
2 what I mean?
3 CO-CHAIR HOMER: Yes.
4 DR. BETHELL: So that's just an
5 idea.
6 CO-CHAIR HOMER: So I can get that
7 up for our team. It's cshcndata.org, right?
8 DR. BETHELL: Yes. And so you go
9 to the actual measures. There is a detailed
10 box at the end that you click on that pops up
11 a pop-up box and then in that there is
12 additional things that you can click on.
13 And we have not summarized all the
14 articles that have been published on these
15 different measures that are showing. And we
16 haven't -- I wasn't clear what the context
17 that you most want to see them for, purposes
18 of, because you have the population health
19 area now. It seems to me that they are most
20 relevant to that, where you are not
21 necessarily trying to pin down the association
22 with the delivery system each child is

1 associated with, but rather looking at
2 population health.
3 So I think that that's the easiest
4 context in which to endorse these measures, if
5 you will. Stratification can occur by type of
6 insurance, by all kinds of other variables,
7 but it was not going to link it up to a health
8 plan or something like that, so that's not the
9 model that would be appropriate to view these
10 measures through, at this time, unless the
11 survey will recommend it to be applied, as a
12 unit of analysis, you know, it's reasonable,
13 but would be a different specification
14 altogether in terms of handling and risk
15 adjustment.
16 CO-CHAIR HOMER: So we are
17 actually getting your survey up on the screen
18 here as we go, and so we should presumably
19 click on the 2005/2006 National Survey, right,
20 of CSHCN?
21 DR. BETHELL: Yes. And while you
22 are doing that, Charlie --

1 CO-CHAIR HOMER: Yes?
2 DR. BETHELL: -- I would just say
3 from a context point of view, all of the
4 survey -- the survey is designed with the
5 close involvement of a technical expert panel
6 sponsored by the Maternal and Child Health
7 Bureau.
8 CO-CHAIR HOMER: Okay.
9 DR. BETHELL: And various tests
10 along the way either through our organization
11 or another organization, often the CDC or the
12 National Center for Health Statistics. So
13 before items and measures are on the pinnacle
14 at all, they go through that process.
15 Not unlike a group like you all, I
16 mean, in terms of the concept of a technical
17 expert panel. So if that gives you any
18 comfort, I want to say you should do that.
19 CO-CHAIR HOMER: We are having a
20 little trouble getting very quickly to your
21 numerator/denominator questions. Can you
22 quickly --

1 DR. BETHELL: Yes. Well, if you
2 go to the measure, I can presume that you know
3 how to do that. We're redesigning the site
4 right now to get a very simple way, but if you
5 go to the core outcomes, key indicators and
6 core outcomes and the chartbook measures?
7 CO-CHAIR HOMER: Yes.
8 DR. BETHELL: Yes. And then there
9 should be a category that you will see,
10 consistently in affecting children's life, for
11 example. You should find that measure on the
12 list.
13 CO-CHAIR HOMER: No, I'm sorry,
14 I'm going in parallel to the screen which is
15 not a good thing to be doing, so I should
16 be --
17 DR. BETHELL: Okay. I wish I was
18 there to help you. Well, anyway, at the end
19 of the -- you find the measure and then at the
20 very end of it, there is a little, I think it
21 is a globe in parenthesis, it's the word
22 details. And if you click on that, the pop-up

1 box comes up that basically walks you through
2 the numerator and the denominator.
3 And keeping in mind that the
4 denominator is all children for whom this
5 question was asked at a population basis. And
6 it is representative of the population of each
7 state. That's the question actually that is
8 about all children who qualify as having
9 special health care needs.
10 So there isn't any exclusion
11 criteria for that one. Care coordination,
12 there are exclusion criteria, for example. So
13 that would be -- that is made as clear as
14 possible in a summary way in that pop-up box.
15 And then if you want to see the actual items
16 that are asked, they are highlighted and you
17 click on them and then it comes up.
18 But this is one of the simplest
19 ways to be able to figure out how to run
20 people without into it literally providing a
21 hard copy document that is -- that's also
22 possible though.

1 CO-CHAIR HOMER: But I just don't
2 see -- while the information is all here and
3 wonderful, it's probably not an efficient use
4 of the Committee's time for me to be working
5 through it. I don't know, Committee, what do
6 you think here?
7 DR. BETHELL: We talked with Tom
8 about this and I think that there is a lot
9 here and it wasn't clear to me exactly how you
10 would want it. And also the time is not
11 sufficient or, you know, I wouldn't want to
12 spend so much time putting it in a format if
13 that wasn't the one you wanted. And so maybe
14 this discussion can be, is there interest in
15 looking at the National Survey, the data
16 produced for the measures they have produced
17 at a population health level.
18 And if so, what would you want,
19 you know, or how would you want to know it?
20 CO-CHAIR HOMER: Kathy?
21 MEMBER JENKINS: It's just going
22 to be a recurring thing for me. I think that

1 the survey itself is, you know, wonderfully
2 developed and rich with information.
3 The question at hand is about
4 child health outcome measures and they have to
5 be well-specified and that's what we need to
6 evaluate. We just need to see the information
7 in sufficient detail that we can do that.
8 I would be willing to allow this
9 issue, definitional issue, about when
10 something that may look to others like a
11 process or structural measure can, in fact, be
12 construed as an outcome measure, but I would
13 like to hear the steward articulate the
14 rationale for that, so that we could all be
15 sure that we understand that.
16 DR. BETHELL: Well, you know, I
17 actually would want to hear more from your
18 guys' angle, because it wasn't clear in the
19 call for measures where you went down that
20 concept. So that's why there are some things
21 in there that I would consider to be -- you
22 know, it depends on what outcome you are

1 talking about: intermediate outcome, long term
2 outcome, or system outcome, like having, you
3 know, experience with the medical home, some
4 people call that an outcome, some people would
5 call that a process. So at least it would be
6 great for us to hear about that.
7 But again, if you are doing to do
8 a survey or if the survey data already exists
9 that you want to stick in, the CSHCN survey is
10 completing good administration, so that you
11 have nine tenths right now, it's not like you
12 go out and just collect data on one piece of
13 it. It's creates a picture of performance for
14 a population of children across process and
15 outcomes and so that's one of the reasons for
16 presenting it as a holistic survey.
17 CO-CHAIR HOMER: Right. So again,
18 Christy, we had discussion earlier on the
19 analogy to CAHPS, so, you know, CAHPS is
20 approved as a tool. And there are a variety
21 of measures that came out of that. And again,
22 I think this Committee is comfortable with the

1 validity of this as, you know, a high quality
2 survey.
3 I think the question that we are
4 still wrestling with, and again, the question
5 we are still wrestling with, is the utility
6 validity -- the validity and utility of some
7 of the specific measures that are derived from
8 this.
9 And then secondarily, whether some
10 of these are best considered processes or
11 outcomes. What I think is, we can quickly go
12 through the list that you gave and figure out
13 which ones are no-brainer outcomes. Like, you
14 know, missing school or impact on function and
15 things like that.
16 And the staff, maybe during lunch,
17 maybe during some other time, we, can pull the
18 specifications or maybe we will have to have
19 a conference call or put some of this off
20 until tomorrow, we can pull the specifications
21 from that from the survey from your website
22 pretty easily, we just haven't done that yet.

1 So I think that's one thing that
2 we need to do. We can go through this list
3 and, like I said, some of them are clearly
4 outcome measures. There are some that are on
5 the fence, like having a medical home.
6 And again, I think those are
7 difficult. I'm not sure how much usefulness
8 it is for us to really spend a lot of time.
9 DR. WINKLER: Charlie, can I just
10 step in?
11 CO-CHAIR HOMER: Yes.
12 DR. WINKLER: Christy, it's Reva
13 Winkler from NQF. Just in other aspects of
14 the outcomes project, we have looked at other
15 measures that are composite measures that have
16 been a mix of process and outcome measures,
17 because it had an element of the outcome
18 measure, it was included.
19 So I don't know that we need to be
20 quite so black and white. I think the issue
21 around this is the question of this measure,
22 as defined and submitted, gives us 15 results.

1 And so I would consider it a multi-part
2 measure, if you will.
3 There is no summary that would
4 turn it into a single composite, so it's a
5 multi-part measure. And I think the question
6 for the Committee is is this a useful, meet
7 all the criteria, measure, given it has 15
8 parts to it? And look at it from that
9 perspective.
10 The fact that it is a mixture of
11 process and outcome measures, I don't think
12 you need to spend a whole lot of time on.
13 CO-CHAIR HOMER: Okay.
14 DR. BETHELL: Yes, I would love to
15 have the opportunity to come back again, too,
16 because there is a composite version of the
17 core outcome for CSHCN, but, you know, how
18 many of the core outcome children have. And
19 it's a system outcome performance measure in
20 that regard.
21 It's really, you know, very
22 minimal. The bar is very low in terms of

1 these measures. These are, if anything,
2 getting positive views of how things are going
3 just by nature of the fact that they are part
4 of the report and they can't be specified, you
5 know, in really, really detailed ways.
6 But when you have a composite,
7 which is proportion of children meeting all
8 five system criteria or 3Q-01, and that is
9 very aligned with issues like having adequate
10 insurance or other process measures and so on
11 and so forth.
12 So there are some ways to score
13 them in a composite-like way, but I didn't put
14 that forward because of time mostly and also
15 because I wasn't sure what would be of
16 interest. But that is possible to do even
17 more than what you are seeing and has been
18 done.
19 CO-CHAIR HOMER: I see no way for
20 us to not, basically, have staff and maybe
21 even some Committee Members working with staff
22 come back to you and try to get -- I know you

1 have the information and I know a lot of it is
2 on the website. I think we are going to have
3 to sort of boil this out, synthesize it, and
4 come back.
5 DR. BETHELL: Yes.
6 CO-CHAIR HOMER: I can't think of
7 any other way around it.
8 DR. BETHELL: Yes. I thought that
9 would happen. I mean, that's sort of -- it
10 was sort of a stretch, you know, to get it to
11 you in the level of detail. I mean, it was a
12 lot of unexpected, you know, and quick
13 turnaround and we did our best. So with your
14 conversation and feedback, we should be able
15 to go to the next step.
16 CO-CHAIR HOMER: This is two in a
17 row that I'm doing that on, so this may end up
18 being unsatisfying. So what is --
19 DR. BETHELL: Yes.
20 CO-CHAIR HOMER: -- the
21 Committee's --
22 DR. BETHELL: Well, that might be

1 reflective of the, you know, quickness and
2 things. And it may just be a natural part of
3 working out what you need.
4 DR. WINKLER: Charlie, as
5 unsatisfying as it might be, if you are not in
6 a position right now to recommend the measure,
7 then Plan B is a definite alternative.
8 CO-CHAIR HOMER: Because I mean, I
9 think, my sense is actually the work group
10 that reviewed this did not feel comfortable
11 enough with what they saw to go forward with
12 it, and I think that's more because the
13 supporting information simply isn't there and
14 unfamiliarity with some of the details of the
15 measure.
16 So I would, rather than have sort
17 of an up or down vote on kind of what we have
18 seen now, we do spend the time and go through
19 that and bring it back.
20 MEMBER PERSAUD: And can I ask in
21 the sort of the way we're looking at the data
22 that we do get to look at the composite

1 measure?

2 DR. BETHELL: Yes.

3 CO-CHAIR HOMER: Sure.

4 MEMBER PERSAUD: The details of

5 that, I would really like to see that.

6 CO-CHAIR HOMER: Okay.

7 DR. BETHELL: Great.

8 MEMBER ZIMA: I would have to say

9 that these last two we put in promising

10 practices, you know.

11 CO-CHAIR HOMER: With the

12 difference between the last one is on this

13 one, there are specifications, we just haven't

14 teased them out. So they exist. This has

15 been used for comparative analysis before.

16 There is actually a website they even go to

17 compare Alaska to Montana, if you want on sort

18 of any one of these metrics and whether there

19 are significant changes over time, et cetera.

20 So I think the difference between

21 this one and the last one is the last group,

22 great concept is being used for a variety of

1 things, but really hasn't been specified in
2 frames that we could use. This one has been
3 specified, but hasn't been presented to us in
4 a way that we can synthesize.
5 MEMBER PARTRIDGE: I have just a
6 quick question for Marina. This is Lee,
7 Christy. You have got a measure with 15 parts
8 is what we are talking about here, I think
9 that was how you described it.
10 As we consider some of the 15
11 parts and will we end up voting? No. I'm
12 trying to figure out if we say we like this,
13 but we really don't like Question 714 and 3,
14 what have we done?
15 DR. WINKLER: This is Reva,
16 Christy. Essentially, since it was submitted
17 as a multi-part measure, it's an all or none
18 from that perspective. However, it could be
19 conditional with removing 6, 12, 13 or
20 whatever, but I don't know if that's something
21 that is, you know, amenable.
22 So it would be part of this

1 discussion back and forth. But given it was
2 submitted as a multi-part measure, that's what
3 you are looking at.
4 MEMBER PARTRIDGE: Right.
5 CO-CHAIR HOMER: Tom?
6 MEMBER McINERNY: Tom McInerny.
7 You know, really, when you look at these
8 measures, there may not be any correlation
9 between the measures at all. And my argument
10 would be we should make this 15 different
11 measures, because someone could have a medical
12 home and a usual source of care and insurance,
13 but they may not have family-centered care or
14 they may not have easy access because, you
15 know, the practice is overwhelmed because they
16 do such a good job.
17 I don't know. But so really the
18 problem is you're going to, as you look at
19 these, you're going to see some are going to
20 be high, some are going to be low, some are
21 going to be in between. And then I don't know
22 how you put it all together. In my mind, it

1 might be better just to say make it clean,
2 make it 15 different measures and just look at
3 each one.
4 MS. McELVEEN: The other thing to
5 keep in mind is they also submitted another
6 large survey measure that is actually
7 comprised of 22 individual measures. And,
8 Christy, you can correct me if I'm wrong, but
9 from what I have gathered is that some of
10 those smaller individual measures do overlap
11 somewhat between the two surveys.
12 And I think the one on care
13 coordination may be a good example of that
14 overlap. So once we get to those other
15 measures, which are all falling under Group 3,
16 if I'm not mistaken, once the Committee kind
17 of looks through each of those individual
18 measures, you may find your ideas and outcomes
19 or decisions may be a little different
20 depending on that.
21 And I also think that it is
22 important that we look at this composite

1 measure that was not submitted, obviously, for
2 the group, but it sounds like that would be
3 valuable for the group to review and possibly
4 as a component of the larger set of measures.
5 CO-CHAIR HOMER: Kathy?
6 MEMBER JENKINS: Maybe it would be
7 useful to try to walk through the Committee
8 process on those item measures because, in a
9 sense, they have presented some of them from
10 that framework, right? I think they have for
11 whatever reason chosen those as probable
12 outcome measures. And we may find ourselves
13 able to approve those and it may also be
14 useful to the group to figure out how to
15 present the broader group in a way that would
16 be helpful.
17 CO-CHAIR HOMER: So are you
18 suggesting that we right now start moving
19 through some of the individual measures within
20 those 15?
21 MEMBER JENKINS: The ones they
22 submitted, yes.

1 CO-CHAIR HOMER: No?

2 MEMBER JENKINS: The ones that

3 were submitted.

4 CO-CHAIR HOMER: The separate

5 ones?

6 MEMBER JENKINS: Yes.

7 CO-CHAIR HOMER: Okay, good.

8 MEMBER JENKINS: Yes.

9 MS. McELVEEN: In other words, the

10 recommendation is tabled for this one.

11 CO-CHAIR HOMER: Okay.

12 MEMBER JENKINS: Right.

13 CO-CHAIR HOMER: Okay. So again,

14 as a little bit with the previous one, the

15 motion on the table, basically, is to table

16 the broad consideration of, actually, both 33

17 and 34, although we actually haven't reviewed

18 33 in detail yet.

19 For us, for staff to work with

20 Christy to come up with a clear presentation

21 with additional background data for that and

22 whether we -- clearly, the sense of the group

1 is we want to see the full composite measure.
2 I think we want some reflection for decision,
3 again, between the steward and the staff as to
4 whether it comes back as separate items or
5 whether it comes back as a multi-part item.
6 I think we are not making that
7 judgment yet as a Committee. So, okay.
8 And then the next idea on the
9 table is moving to some of the individual
10 items.
11 MS. McELVEEN: Would 35 actually
12 be the next one?
13 CO-CHAIR HOMER: Okay. So do you
14 want to put up the summary of 35? 35 is
15 Children who take medication for ADHD,
16 emotional or behavioral issues. Anyone who
17 was on that work group want to describe either
18 their impressions or walk us through the
19 assembled vote of the Committee, which is
20 sitting up on the screen?
21 MEMBER SCHWALENSTOCKER: Charlie,
22 I need to actually pull up the thing on my

1 computer, because I can't see the screen, but
2 my initial take on this measure was, it seemed
3 more like a process measure to me than an
4 outcome measure. So with that brief comment,
5 I will try to find my document here.
6 MEMBER ZIMA: Oh, we were a small
7 sample size.
8 MEMBER SCHWALENSTOCKER: Yes.
9 MEMBER ZIMA: And psychiatry gets
10 even smaller.
11 CO-CHAIR HOMER: Yes.
12 MEMBER ZIMA: But I think that my
13 initial impression was not -- was lukewarm
14 only because I looked again at the numerator
15 details. And what I struggled with most was
16 that medication is often indicated for ADHD,
17 but it's not necessarily indicated for this
18 other broad group, other emotional or
19 behavioral issues.
20 And so I think again it kind of
21 highlights taking this issue and putting it on
22 sort of the next step, future steps, because

1 there is variation and a level of evidence for
2 treatment for particular psychiatric
3 disorders.
4 And I think we are getting caught
5 up in sort of a dynamic where initially we
6 were describing mental health problems,
7 psychosocial problems, you know, mental health
8 problems, behavioral, emotional or behavioral,
9 serious emotional behavioral disorders, but
10 there is now a little bit of a trickling where
11 maybe we can better specify diagnosis and link
12 that to a particular recommended treatment.
13 We are not there, but again when
14 you lump this together, for me, it makes it
15 very problematic to make any sort of
16 assessment of whether that child got good
17 care.
18 MEMBER FISHER: Don't you think --
19 you said about the controversy is that looking
20 at the age group, 2 to 17, you started talking
21 about mental health problems and things. You
22 really are going to get into off-label use of

1 medications, and it is hard to second guess.
2 And so, I mean, that really brings a
3 controversy when people are trying to deal
4 with us now what do you do with the children,
5 say, at three that I know some that really
6 needed medications, but you don't really want
7 to put them in this group.
8 They may be getting good care, but
9 that's just like you said, that is not where
10 you want to go.
11 MEMBER PERSAUD: Yes, I mean, I'm
12 really worried about having the 2 to 3 or 4
13 year-olds mixed up in this group, because I
14 think the literature is unclear about whether
15 you should be really calling it ADD. And I
16 think you are definitely at off-label use of
17 meds. And I don't agree that medications for
18 other emotional disorders should be in this
19 group.
20 This group needs to be clean and I
21 think the most latest discussions in the ICD-
22 9, 10, ICD-10 about the elimination of bipolar

1 disorder that became a big group, that is
2 another group that is going to be mixed up in
3 here, that people are using medications on
4 where that practice is really being looked at
5 right now as to whether that is good practice.
6 MEMBER ZIMA: There is also one
7 more moving target, I think, when we think
8 about child mental health. And again, this is
9 probably for tomorrow's discussion, and that
10 is the changes in the DSM-V.
11 So you know, this debate about the
12 age, well, they have thrown out the age of
13 onset for the ADHD diagnosis. But again, I
14 don't think the evidence is there for the
15 younger child.
16 And so then if you are going to be
17 talking about the controversy of bipolar
18 disorder, then that's going to also again, I
19 think, for future steps and probably for many
20 years, start thinking about, well, how in the
21 world did they get this dysregulation syndrome
22 diagnosis that is being proposed?

1 So just --

2 MEMBER FISHER: I think there is

3 also, when you bring that up, if you have a

4 really clean -- and we are talking about ADHD,

5 then that's an opportunity to look at to see

6 about quality care in those kids, because

7 there is some evidence that kids are being

8 over-medicated.

9 And so, you know, you're right.

10 We need to look at one thing, make it really

11 clean, define it, so we can do some quality

12 improvement.

13 MEMBER RAO: I just want to echo

14 that a little bit. I mean, I think this is a

15 measure that is very prone to abuse. I mean,

16 there is lots of children with ADHD who

17 probably don't need to be on medicine. So if

18 this measure goes out and says well, 8 percent

19 of your kids are treated and 92 percent are

20 not, is that good or bad is really going to be

21 difficult to say, at this point.

22 MEMBER ZIMA: You know, it's

1 interesting, because the data might suggest
2 sometimes it is over-medicated if you look at
3 Medicaid claims data, but when you look at
4 actual treatment adherence, it's incredibly
5 low.
6 And so, I think, again this goes
7 to sort of tomorrow's discussion, because
8 there has to be much more emphasis on the
9 family-centeredness and the parent preference
10 for treatment around mental health problems
11 and how that also changes over time for that
12 parent and that child.
13 And so I think, you know, on the
14 table again for maybe future steps is, how do
15 we also integrate parent preference in
16 treatment when thinking about scoring the
17 indicator?
18 CO-CHAIR HOMER: So I think from a
19 threshold perspective, I mean, no one could
20 argue that the use of psychotropic drugs in
21 children is an important issue and there are
22 many controversial elements to it.

1 But this measure, that is the
2 proportion of children with some form of
3 behavioral problem who are on medication, one
4 could really argue whether this meets
5 threshold criteria for importance, because the
6 meaning of the measure is so unclear.
7 So I would actually propose a
8 quick threshold vote on this on the importance
9 criteria. And, Reva, would you call it,
10 please? Let me know if you think I'm
11 misinterpreting importance, but at least from
12 my perspective, I'm having a hard time lining
13 up this measure with any concerns people might
14 have, so I would like to say it doesn't meet
15 the criteria for importance and we could not
16 even get into the issues of feasibility and
17 usability and specifications and all that.
18 CO-CHAIR WEISS: Maybe this is
19 just a different way to ask the same question,
20 but as a non-clinician, my question is if we
21 know the answer, what do we know? How do we
22 deal with it? I mean, maybe it's patient

1 adherence. So I guess I would second the
2 comments that Charlie has made about maybe
3 this doesn't meet the most fundamental of all
4 of our thresholds.
5 MEMBER JENKINS: I just wondered
6 if the measure developer wanted to respond
7 before we voted, in case we missed something?
8 CO-CHAIR HOMER: Good. Christy,
9 are you there? Is the phone still there?
10 Marlene, are you still there?
11 MEMBER MILLER: I'm still here.
12 CO-CHAIR HOMER: Oh, good. Okay.
13 Just wanted to make sure the phone was still
14 working.
15 DR. WINKLER: Christy, said she
16 would be in and out.
17 MEMBER JENKINS: Yes.
18 CO-CHAIR HOMER: So, okay.
19 MEMBER JENKINS: It doesn't
20 matter.
21 CO-CHAIR HOMER: So anyhow, I
22 would propose that we have a vote on

1 importance. All those who would vote that
2 this is sufficiently -- and I'll do it on the
3 positive this way. Let's say this is
4 sufficiently important to go forward and that
5 it meets the threshold criteria, raise your
6 hand. Okay.
7 DR. WINKLER: Marlene?
8 MEMBER MILLER: Just to clarify,
9 does this may mean that more information will
10 be forthcoming then on the stuff we have
11 talked about?
12 CO-CHAIR HOMER: This one, no. We
13 are saying if this is voted no --
14 DR. WINKLER: That's it.
15 CO-CHAIR HOMER: -- then we don't
16 want to know any more about this question, you
17 know, about this particular item.
18 MEMBER MILLER: So if we say yes,
19 then more information will come?
20 CO-CHAIR HOMER: Yes, then we have
21 to have a broader conversation about this
22 measure.

1 MEMBER MILLER: All right. Yes,
2 then I vote yes.
3 DR. WINKLER: Okay. That's one.
4 CO-CHAIR HOMER: Okay. All those
5 who vote that no, this does not meet the
6 importance threshold for further
7 consideration? Allan, are you voting?
8 MEMBER LIEBERTHAL: I'm having
9 some struggle here.
10 CO-CHAIR HOMER: Okay.
11 DR. WINKLER: Are you abstaining,
12 Allan?
13 MEMBER LIEBERTHAL: I'm
14 abstaining.
15 CO-CHAIR HOMER: Okay. All right.
16 MEMBER LIEBERTHAL: I just lost
17 all my reviewing reports.
18 CO-CHAIR HOMER: Okay. So one in
19 favor, 13 against, 1 abstained.
20 DR. WINKLER: One abstained.
21 CO-CHAIR HOMER: Okay. So it
22 doesn't meet. Ellen?

1 MEMBER SCHWALENSTOCKER: Charlie,
2 I'm sorry, not to put too fine a point on it.
3 It's not that I would say I don't want to move
4 it forward because it's not important. I
5 think it's an important issue, but I think --
6 so it's not right, in my mind, to say it's not
7 important. It just doesn't meet our other
8 criteria for what we are trying to measure.
9 Is that --
10 CO-CHAIR HOMER: Right. I knew I
11 was stretching the --
12 MEMBER PERSAUD: I think it is
13 important because of the way it is --
14 MEMBER SCHWALENSTOCKER: Yes.
15 MEMBER PERSAUD: Okay.
16 MEMBER SCHWALENSTOCKER: The way
17 it's written.
18 MEMBER PERSAUD: I mean, every
19 issue is important. This measure isn't
20 constructive in a way that it meets the
21 criteria.
22 So for the record, I think the way

1 this measure is constructed, that's why it is
2 not important, because the construction
3 doesn't meet importance, not that the topic
4 isn't important. And I don't think that's
5 what our charge is.
6 DR. WINKLER: Also just to
7 reassure everyone, NQF has already endorsed
8 several measures, process measures, around
9 management of children with ADHD and
10 appropriate follow-up care for those on
11 medication. And so it's not as if the topic
12 doesn't have some measures associated with it
13 already.
14 CO-CHAIR HOMER: Okay. Let's move
15 on. Hey, we got something done. That's good.
16 How are we doing for time?
17 MS. McELVEEN: Okay. So we are
18 about 12:20. I think it would be worth going
19 through another measure that, again, was
20 submitted by CAHMI, an individual measure.
21 And after that, we can go ahead and probably
22 break for lunch, but if we could get through

1 that last bit of measure, we would have at
2 least completed what we said we were going to
3 complete before lunch. So that's good.
4 So this is Measure 37 and this is
5 a measure, Children Living with Illness: The
6 Effects of Condition on Daily Life. And this
7 measures the extent to which conditions of
8 children with special health care needs
9 results in limitations of their daily
10 activities, despite health care services
11 received.
12 So again, we will open this up to
13 the group for discussion looking at, of
14 course, importance and scope as kind of the
15 first items on there.
16 CO-CHAIR HOMER: So again, could
17 we hear from the --
18 MEMBER ZIMA: I guess my biggest
19 concern was I thought maybe this was more of
20 a severity indicator and that depending on the
21 type of -- depending on the care, some
22 children would get better and some people

1 would remain or maintain a certain level of
2 functioning.
3 And it didn't seem like we could
4 really -- I could really interpret the meaning
5 of this indicator the way it was written.
6 MEMBER JENKINS: Are you looking
7 for risk adjustment?
8 MEMBER ZIMA: No. I was thinking
9 more in terms of, again, more clinically. And
10 maybe this is a problem. But some disorders
11 don't get better and will always have a
12 certain limitation in functioning. And even
13 under good care, for example, like an autistic
14 child, you are going to maintain a certain
15 level of functioning.
16 And whereas a striking example
17 would be an ADHD kid with proper medication,
18 behavioral treatment and special ed, they
19 might get -- their functioning might improve
20 dramatically. So I wouldn't be able to tease
21 that out.
22 MEMBER FISHER: Also, to add to

1 that, there are kids with special health care
2 needs that are severe who are going to get
3 worse. And so the idea is that you have to
4 support them as they get worse, but that's
5 even harder to evaluate. They need good care,
6 but they are going to deteriorate.
7 CO-CHAIR HOMER: All that being --
8 well, okay. Maybe to be more formal, should
9 we first wrestle with the importance issue?
10 Do you think this is an important topic? That
11 is, the problem is prevalent enough, there is
12 likely to be some variability across
13 jurisdictions or systems. There may be
14 disparities. This may reflect disparities in
15 care. Again, those are the criteria for
16 importance.
17 Again, first there is the
18 threshold for then do we go on to some of the
19 other aspects?
20 MEMBER PARTRIDGE: I don't have
21 the specs in front of me. Can we answer some
22 of those questions from the materials

1 submitted?
2 CO-CHAIR HOMER: What it says is,
3 38.5 percent of children with special health
4 care needs, health conditions have a moderate
5 effect on their daily activities.
6 MEMBER PARTRIDGE: Does that
7 surprise you?
8 CO-CHAIR HOMER: No.
9 MEMBER PARTRIDGE: Okay.
10 CO-CHAIR HOMER: But there is an
11 indication that this is --
12 MEMBER PARTRIDGE: Right.
13 CO-CHAIR HOMER: -- a big deal as
14 opposed to a little deal.
15 MEMBER PARTRIDGE: Correct. So
16 then I think I would want to know, given that,
17 what more information do we have?
18 CO-CHAIR HOMER: The range across
19 states is from 18 percent in Iowa to 30
20 percent in Oregon. Now, so there is
21 variability across states.
22 MEMBER PARTRIDGE: And we don't

1 know how that correlates with the conditions
2 we are talking about?
3 CO-CHAIR HOMER: Well, we do know
4 that poor children have conditions that
5 consistently affect their daily lives more
6 than twice as often, 35 to 15 percent. Kids
7 with a medical home are twice as likely to
8 have health conditions that consistent, so
9 that actually -- kids without a medical home
10 are twice as likely to have a health condition
11 that consistently affects their lives, 30 to
12 15 percent. So there is some.
13 MEMBER PARTRIDGE: Some.
14 CO-CHAIR HOMER: If you do have a
15 medical home --
16 MEMBER PARTRIDGE: Right.
17 CO-CHAIR HOMER: -- you are half
18 as likely to have a health condition.
19 MEMBER PARTRIDGE: Right. So you
20 get a -- you can drill down, in other words,
21 and look at different dimensions based on the
22 answers to these questions.

1 CO-CHAIR HOMER: Yes.
2 MEMBER LIEBERTHAL: Unfortunately,
3 my USB port seems to have died or I'm having
4 trouble, so I'm not able to look at the
5 specifications very well. But the way I read
6 just the summary of the question, this refers
7 to a population of children who are getting
8 services and are still having their -- their
9 lives are still affected. Am I reading it
10 correctly or not?
11 Because if there -- because if I'm
12 reading it correctly, what you are dealing
13 with is the base line of their special health
14 care need and, therefore, all you are
15 identifying is the floor of what is possible.
16 Now, if I'm not reading it
17 correctly --
18 CO-CHAIR HOMER: I don't think --
19 MEMBER LIEBERTHAL: -- then I
20 don't know what the wording is.
21 CO-CHAIR HOMER: I don't think --
22 MEMBER PERSAUD: The denominator

1 is all children ages 0 to 17 who have special
2 health care needs.
3 CO-CHAIR HOMER: Special health
4 care needs is either because you have --
5 MEMBER PERSAUD: That's the full -
6 -
7 CO-CHAIR HOMER: -- the condition
8 or because you have --
9 MEMBER LIEBERTHAL: Okay.
10 CO-CHAIR HOMER: -- received
11 services that are more than other children.
12 MEMBER LIEBERTHAL: Okay.
13 CO-CHAIR HOMER: Or that you have
14 some form of therapy.
15 MEMBER LIEBERTHAL: Okay. And I
16 can't get mine because I don't have the
17 specifications in front of me.
18 CO-CHAIR HOMER: No, not risk, but
19 -- I'm sorry, Allan?
20 MEMBER LIEBERTHAL: I don't have
21 the specifications in front of me to see
22 what's going on with it.

1 CO-CHAIR HOMER: Yes, I'm trying
2 to find it.
3 MEMBER PERSAUD: If you actually
4 scroll down to the specs, scroll down to 2A or
5 whatever.
6 MEMBER JENKINS: There you go.
7 CO-CHAIR HOMER: Do you have any--
8 MEMBER PERSAUD: I'm trying to
9 think about the answer to Bonnie's question
10 about severity and whether -- and I don't know
11 how this questionnaire is constructed, but
12 just trying to think about if the
13 questionnaire is constructed consistent with
14 what -- with good care, someone with
15 disabilities might have, if it's constructed
16 around -- I mean, I'm thinking except for
17 maybe ventilated assisted patients, even those
18 that are near vegetative with tracheostomy
19 still can be transported to school and spend
20 the day in school and be cared for.
21 Would that be -- you know, if they
22 can go to school and be cared for without

1 multiple interventions, would that be regarded
2 as the acceptable level of daily activity?
3 And if that's impaired, it is at issue. It's
4 I think just a matter of whether the question
5 is asked appropriate to the best possible
6 outcome from someone with that level of
7 disability.
8 CO-CHAIR HOMER: I was just trying
9 to put the actual question up on the screen.
10 MEMBER JENKINS: Yes, I was just
11 going to say that my take on this is that what
12 we are struggling with is whether or not this
13 is all crafted scientifically, so that we
14 could understand variation as a quality
15 measure and that those are really kind of part
16 of the scientific issue here.
17 But that it is meeting my criteria
18 for importance as crafted, as it is even
19 meeting my criteria as an outcome measure.
20 CO-CHAIR HOMER: Great.
21 MEMBER JENKINS: And we are
22 hearing about gaps. You know, it may fall

1 down when we talk about the scientific issues
2 in terms of Donna's issue around is the
3 question crafted in a way that all people
4 would answer it and Bonnie's around what I
5 would regard as risk adjustment and then the
6 trajectory of disease and what is preventable.
7 Those are different issues to me,
8 but I think my answer to you, Charlie, is yes,
9 it passes the first threshold for getting into
10 that broader discussion.
11 CO-CHAIR HOMER: Yes, right. So
12 why don't I call a vote on whether people
13 think this is sufficiently important to
14 proceed with the conversation, so that we can
15 go on. So we will have a vote on that.
16 All who vote yes, this meets the
17 threshold criteria for importance, so that we
18 can then go into the more detailed issues
19 around validity and feasibility, usability, et
20 cetera. So all those who vote yes?
21 DR. WINKLER: Marlene?
22 MEMBER MILLER: Yes.

1 DR. WINKLER: Thank you.
2 MS. McELVEEN: That's 14 yeses,
3 and that was everybody.
4 CO-CHAIR HOMER: Okay. Good. Let
5 me just read the items. Let me just read the
6 items just because I'm so proud of having
7 found it.
8 It says during the past 12 months,
9 how often have blank medical behavioral or
10 other health conditions, emotional development
11 or whatever it is, how often has Suzie's
12 condition affected his or her ability to do
13 things other children their age does? That's
14 sort of the question.
15 Okay. So it's a very broad
16 question.
17 CO-CHAIR WEISS: So affected could
18 be positive or negative. Either made it
19 possible or inhibited it.
20 CO-CHAIR HOMER: Yes, at least
21 that's Question CQ, whatever it is, 2. And it
22 also says Question 3 is supposed to be in

1 here, right? So anyhow, C3Q, Section 3,
2 Question 2, that was the item. I can try to
3 find what Question 3 is as well. But at least
4 you get some sense. Maybe that helped, maybe
5 it didn't, but now you know what the question
6 is that we are dealing with.
7 CO-CHAIR WEISS: We know the
8 population.
9 CO-CHAIR HOMER: So why don't we
10 then continue? We have talked about it meets
11 the importance criteria. What are the next
12 set of criteria that we should be considering?
13 Scientifically acceptable. So
14 comments from the reviewers as to its level of
15 scientific acceptability?
16 MEMBER PERSAUD: So I do see in
17 here that it specifically says it is not risk
18 adjusted and so when you gave that opening
19 question and it's not risk adjusted, I think
20 it doesn't answer Bonnie and my concern about
21 appropriateness and being able to assess the
22 results, because they don't match the

1 expectations, I think, of the need,
2 especially, you know, their function or what
3 their true function could be.
4 MEMBER DOCHERTY: Isn't it the
5 validity question? Is it really measuring
6 their ability to improve their daily living as
7 compared to other children their age or
8 compared to children with similar conditions?
9 MEMBER PERSAUD: Well, I think
10 that's really --
11 CO-CHAIR HOMER: But if you are --
12 the next item, by the way, and I'm not quite
13 sure how different it is, does ask is medical
14 behavior or other health condition affect his
15 or her ability to do things a great deal, some
16 or very little? So I guess that's the -- the
17 first one is does it affect it and then the
18 next question is does it affect it a great
19 deal, you know, somewhat or very little?
20 That's sort of the severity of
21 impact on function or on daily life.
22 Let's go back to Kathy's earlier

1 observations though. If this is applied at a
2 population level, so if you are comparing
3 Alaska and Indiana or Ohio and Oregon, which
4 is, I guess, where they were comparing, would
5 you expect that at a large enough population
6 levels that big a difference in distribution
7 of health and disease that it would threaten
8 its validity?
9 I mean, I guess if the sickest
10 patients in the country moved to Oregon or,
11 you know, Des Moines or whatever, it might,
12 but otherwise, it's probably hard to imagine.
13 MEMBER FISHER: I think -- oh, I'm
14 sorry.
15 CO-CHAIR HOMER: I'm sorry.
16 Nancy, go ahead.
17 MEMBER FISHER: Go ahead. You
18 were first.
19 CO-CHAIR HOMER: Tom?
20 MEMBER McINERNY: Well, I think
21 there is some evidence that certain states
22 have a richer set of benefits for patients who

1 have special health care needs. And so
2 patients will preferentially gravitate to
3 those states. And that could certainly skew
4 your results.
5 CO-CHAIR HOMER: Okay.
6 MEMBER FISHER: I was going to say
7 the same thing. And to add to it, you have to
8 look at whether --
9 CO-CHAIR HOMER: Turn your mic on,
10 please.
11 MEMBER FISHER: -- you are on the
12 east coast or the west coast. And the reason
13 why I say that is about gravitation, because
14 people forget Wyoming only has a half a
15 million people.
16 CO-CHAIR HOMER: Right.
17 MEMBER FISHER: And then Montana,
18 which is huge, has a million. So the
19 resources there are less and those people will
20 move to where the resources are.
21 So let me give you an example.
22 You can move out to Seattle and there are a

1 lot of people there with Huntington's Disease
2 that have moved from other places because of
3 the expert that is there, a neurologist who is
4 also a geneticist, so you get all of these
5 people that move in.
6 So you know, it depends on what
7 portion of the country and how big your state
8 is and how populated.
9 MEMBER PARTRIDGE: Charlie, I
10 think I would also add there will be
11 differences in the incidents of certain
12 conditions based on the population of that
13 state. In the District of Columbia I had a
14 fairly significant rate of sickle-cell.
15 CO-CHAIR HOMER: Yes.
16 MEMBER PARTRIDGE: That is not
17 likely to be true in other parts of the
18 country.
19 MEMBER FISHER: We don't see
20 hardly any of that.
21 MEMBER PARTRIDGE: Right. If you
22 were -- you know, that springs to mind because

1 of my own experience, but I'm sure there are
2 other characteristics and environmentally-
3 caused conditions and so on.
4 MEMBER FISHER: One other thing is
5 I was looking at the citations they gave and
6 we were talking about risk adjustment, but
7 it's interesting in the citations that they
8 gave for the group that they are talking
9 about, they were dividing them into subgroups
10 for comparison.
11 CO-CHAIR HOMER: Right. You can
12 do that.
13 MEMBER FISHER: Yes. And so the
14 question to me that is very important when you
15 are looking at this. And they even, you know,
16 bring it up when you look into the system.
17 CO-CHAIR HOMER: Right. And so I
18 mean even as we are speaking I'm sitting here
19 stratifying the national data or the
20 Mississippi data by raising things like that.
21 MEMBER FISHER: Yes.
22 CO-CHAIR HOMER: So one could

1 certainly do that. Okay. So I'm still
2 hearing a lot of concern about the
3 scientific --
4 MEMBER FISHER: That raises
5 poverty.
6 CO-CHAIR HOMER: -- validity and
7 the scientific merit of the measure.
8 MEMBER JENKINS: Specifically
9 around confounding by the individual patients
10 that are part of the numerator.
11 CO-CHAIR HOMER: Okay. All right.
12 Any other elements? That's the scientific
13 credibility. It sounds like we have got a
14 clear sense.
15 DR. WINKLER: We should vote on
16 it.
17 CO-CHAIR HOMER: Should we vote on
18 the whole measure based on that?
19 DR. WINKLER: Each criterion.
20 CO-CHAIR HOMER: Okay. You want
21 to talk about usability next?
22 DR. WINKLER: We need a vote from

1 the Steering Committee on each of the major
2 criteria.
3 CO-CHAIR HOMER: Okay.
4 DR. WINKLER: Going out.
5 CO-CHAIR HOMER: We haven't
6 consistently been doing that.
7 DR. WINKLER: You haven't gone
8 through them yet. You haven't got that far.
9 CO-CHAIR HOMER: Okay. So then on
10 the scientific merit, all those who believe it
11 has sufficient scientific merit to move
12 forward?
13 DR. WINKLER: Yes, completely.
14 CO-CHAIR HOMER: Completely?
15 MEMBER JENKINS: Does it have to
16 be completely?
17 DR. WINKLER: No. You have
18 choices, remember?
19 MEMBER JENKINS: Well, what are we
20 voting on?
21 CO-CHAIR HOMER: So we are voting
22 on the scientific merit of this measure and it

1 needs to be at the completely. Does it
2 completely fulfill the criteria for
3 scientific?
4 MS. McELVEEN: And the choices are
5 completely, partially, minimally, not at all
6 or not applicable.
7 CO-CHAIR HOMER: Right.
8 DR. WINKLER: So I get zero for
9 completely. How about partially meets the
10 criteria?
11 CO-CHAIR HOMER: I'd say partially.
12 DR. WINKLER: One, two, three.
13 Marlene?
14 MEMBER MILLER: I believe
15 minimally.
16 DR. WINKLER: Okay, fine. So
17 that's three for partially. How many are
18 minimally? One, two, three, four, five, six,
19 seven, eight, nine, ten, eleven, Marlene is
20 twelve. Okay. That's it.
21 CO-CHAIR HOMER: Moving on to the
22 next criteria, which is usability. And the

1 subsets for --

2 MS. McELVEEN: We have to go back

3 to the --

4 CO-CHAIR HOMER: So does it

5 provide meaningful, understandable and useful

6 information?

7 DR. WINKLER: Right.

8 CO-CHAIR HOMER: Yes, I mean, the

9 sub-categories here are meaningful,

10 understandable and useful information in

11 relation to other NQF-endorsed measures, level

12 of harmonization, distinctive and added value,

13 right, those are the --

14 DR. WINKLER: Yes, those are them.

15 CO-CHAIR HOMER: Those are the

16 subsets of that.

17 MEMBER CLARKE: I would say that

18 actually mixing the scientific merit really

19 kind of makes this sort of moot.

20 CO-CHAIR HOMER: The rest is sort

21 of moot.

22 MEMBER CLARKE: And it may be that

1 we could have a discussion about is there a
2 stratification fix for the scientific merit
3 that we could stipulate.
4 CO-CHAIR HOMER: That's a good
5 idea.
6 MEMBER JENKINS: I agree that they
7 are correlated and that, to me, this whole
8 thing was a lot about usability, which is
9 about actionability and to the same extent
10 that we had trouble understanding the
11 subpopulations of the measure, et cetera, it
12 fell down to be in the usability action
13 ability.
14 CO-CHAIR HOMER: But going back to
15 David's question, are there recommendations
16 that we could come up with as to how this
17 measure could be fixed, so that it could, in
18 fact, be usable and provide what you would
19 consider valid data?
20 I mean, what kind of
21 stratification variable, for example, would
22 you want to know in order to do this?

1 MEMBER CLARKE: Diagnosis and
2 activity expectations.
3 MEMBER JENKINS: And potentially
4 the extent to which those are modifiable. I
5 think that there is ways through either
6 exclusions or through categorizations that one
7 could craft a very interesting outcome measure
8 which is much more actionable. It would be
9 some work for them to do it.
10 CO-CHAIR HOMER: Yes, I'm
11 wrestling a little with, you know, the
12 movement in the field for kids with special
13 health care needs has been to the sort of
14 non-categorical approach that is that the
15 issues around the care and to some extent
16 outcomes, but the care of kids with chronic
17 illness is more common across conditions.
18 And the use of diagnostic
19 categories is usually pretty poor in
20 identifying kids.
21 MEMBER JENKINS: If I could say,
22 and I'm sure you will see some of this in our

1 measures tomorrow, that you can sometimes
2 group patients together or children together
3 in categories for the outcome of interest --
4 CO-CHAIR HOMER: Yes.
5 MEMBER JENKINS: -- regardless of
6 diagnosis. So here the issue has to do with
7 more of the expectations of the effect of the
8 condition on the lifestyle and the trajectory
9 of disease and the ability to impact that by
10 medical treatment.
11 So regardless of diagnosis, those
12 are really the categories that would be
13 necessary to understand the variation in the
14 outcome. They may not be by diagnosis or they
15 may.
16 CO-CHAIR HOMER: Okay. I guess I
17 take from that actually that it would be a
18 quick fix of this measure is not likely, that
19 that's actually a pretty complicated set of
20 questions.
21 DR. WINKLER: Yes.
22 CO-CHAIR HOMER: Okay. So I think

1 so let's then keep -- so that we can check off
2 all the check boxes, make sure that we have
3 gone through the usability criteria.
4 Why don't we call a vote on how
5 many feel it meets completely usable?
6 DR. WINKLER: Marlene?
7 MEMBER MILLER: Yes?
8 DR. WINKLER: You're not voting
9 completely, are you?
10 MEMBER MILLER: No, I'm not.
11 DR. WINKLER: Thank you.
12 MS. McELVEEN: Next one?
13 CO-CHAIR HOMER: Partially usable?
14 Partially usable, anyone?
15 DR. WINKLER: Okay.
16 CO-CHAIR HOMER: Minimally?
17 DR. WINKLER: One, two, three,
18 four, five, six, seven, eight, nine, ten,
19 eleven, twelve, thirteen. Marlene?
20 MEMBER MILLER: Yes.
21 DR. WINKLER: Okay. So that's 14.
22 CO-CHAIR HOMER: And not at all.

1 DR. WINKLER: And you're the not
2 at all. Okay.
3 CO-CHAIR HOMER: All right. And
4 then the last one is is it feasible? Data
5 generated by product of care or other
6 electronic sources, appropriate specifications
7 of exclusions, susceptible to inaccuracies?
8 And I guess I would argue that if
9 this is actually just derived from the
10 national survey, it is actually extremely
11 feasible, because the federal government
12 produces the survey on a regular basis and
13 there is an online data query tool that anyone
14 who wants to get it at this population level
15 can get it.
16 So that would be -- so those who
17 feel it is completely feasible? Completely
18 feasible?
19 MEMBER FISHER: Okay. All right.
20 MS. McELVEEN: Show of hands?
21 Those who say completely feasible hands up
22 high, please? Thanks. All right. Nine, ten.

1 CO-CHAIR HOMER: You should be
2 strong.
3 MEMBER LIEBERTHAL: Just a
4 comment. It is feasible to do, but just
5 because it's feasible, what do you do with it
6 once you get it?
7 CO-CHAIR HOMER: Well, that's
8 the --
9 MEMBER LIEBERTHAL: And we are
10 inundated with data that is feasible, but then
11 you have to figure out what to do with it.
12 MEMBER FISHER: Yes, but it's
13 still feasible.
14 CO-CHAIR HOMER: Fair enough. We
15 are just trying to say that these are somewhat
16 distinguishable categories. We are trying not
17 to do the global subjective judgments.
18 MEMBER DOCHERTY: My only problem
19 with the feasibility category is the
20 inaccuracy piece of it, that it is hard to say
21 something that has some potential for
22 inaccuracy --

1 CO-CHAIR HOMER: Yes.
2 MEMBER DOCHERTY: -- because of
3 the way the question is worded and the
4 denominator then can be feasible.
5 CO-CHAIR HOMER: Okay. So we have
6 how many said --
7 MS. McELVEEN: Ten.
8 CO-CHAIR HOMER: 10. So let's
9 move on to partially.
10 DR. WINKLER: One, two, three.
11 MEMBER MILLER: I'll vote partial.
12 CO-CHAIR HOMER: Okay. So we have
13 four, five. We have five. So that means that
14 no minimally and no -- did I get that right?
15 No minimally and no not at all.
16 So do we need an overall vote?
17 DR. WINKLER: Yes.
18 CO-CHAIR HOMER: We do need an
19 overall vote. So how many would vote in favor
20 of recommending this measure to go forward?
21 It's out of order. No, that's fine. I see
22 none in favor. How many who vote no, not to

1 recommend it going forward in this current
2 state?
3 MEMBER MILLER: I'm a no.
4 CO-CHAIR HOMER: Okay.
5 MS. McELVEEN: Okay. We fully got
6 through one measure, so we are moving along
7 well.
8 CO-CHAIR HOMER: Moving right
9 along.
10 MS. McELVEEN: Lunch is set up in
11 this room exactly where the breakfast was set
12 up. So we are going to take about a 15 minute
13 recess. If you could get your lunch and eat,
14 phone calls or whatever and come back, and we
15 will reconvene.
16 (Whereupon, the meeting was
17 recessed at 12:45 p.m. to reconvene at 1:30
18 p.m.)
19
20
21
22

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

2 1:30 p.m.

3 CO-CHAIR HOMER: All right. Well,

4 why don't we reconvene. I hope everyone

5 enjoyed their delicious lunch and had a chance

6 to chat. The food was very nice. The sun is

7 shining. This is good.

8 We do have a number of guests that

9 we haven't had the chance to say hello to. I

10 wonder if our guests, that maybe some of us

11 met during lunch, could just introduce

12 themselves.

13 DR. BERGERSEN: My name is Lisa

14 Bergersen. I'm a pediatric interventional

15 cardiologist and I'm from Children's Hospital,

16 Boston.

17 CO-CHAIR HOMER: Thank you very

18 much.

19 DR. RAUSCHER: Hi. Nina Rauscher.

20 I'm also from Children's Hospital, Boston.

21 I'm the measure steward for the four measures

22 that are going to be presented tomorrow.

1 Thanks.
2 DR. DEINARD: I'm Amos Deinard
3 from the Department of Pediatrics and School
4 of Public Health at the University of
5 Minnesota.
6 CO-CHAIR HOMER: That is a perfect
7 segue. Thank you for being here. The first
8 measure that we are going to review this
9 afternoon is the one that you were the --
10 DR. DEINARD: That's why I'm
11 sitting at the head of the table right now.
12 It was all scripted.
13 CO-CHAIR HOMER: So this measure
14 is OT3-049. It goes by the name of Primary
15 Care Prevention Intervention as Part of Well
16 Child Care. This measure was reviewed by Work
17 Group 1. The scores are reflected on the
18 board. Would anyone in Work Group 1 like to
19 talk this one through?
20 MEMBER MILLER: Charlie, what's
21 the number of it again?
22 CO-CHAIR HOMER: Forty-nine.

1 MEMBER CLARKE: As far as impact
2 we felt it is a condition that affects a large
3 number of children. There is pretty good
4 evidence that fluoride varnish has a very
5 positive effect in reducing Caries disease.
6 Obviously this is a significant
7 problem a lot in low income populations. I
8 guess one of the reviewers identified the
9 issue that it's not real clear how available
10 the fluoride varnish is to PCMPs but it must
11 be fairly available, I guess.
12 DR. DEINARD: Would you like me to
13 answer that? I can provide anyone in this
14 room who sends me his or her email address
15 with a list of vendors who will sell to
16 medical clinics, public health nurse agencies,
17 etc., without any questions asked. It's
18 readily available.
19 The more you buy the lower the
20 price. It's got a two-year shelf life. You
21 can buy it in good-size labs for 85 cents a
22 dose or something like that. It's very

1 inexpensive. It takes less than five minutes
2 to put on. In many states it can be delegated
3 to a CMA or an LPN or a MA to actually do the
4 varnishing.
5 MEMBER CLARKE: Do we have to vote
6 on impact?
7 CO-CHAIR HOMER: We do. The work
8 group felt that this was important that there
9 was a gap in performance, at least either
10 completely or partially and that the treatment
11 related to outcome. Are there any questions
12 from anybody about the importance?
13 MEMBER LIEBERTHAL: Yes, I do.
14 What was the -- did the ADA have a policy
15 statement on this? Unfortunately I would have
16 to go to the AAP site because I don't remember
17 if the AAP has a policy statement on this.
18 DR. DEINARD: The AAP not only has
19 a policy statement that physicians should be
20 doing this but it also has an oral health
21 initiative group, one of the top three
22 projects of the AAP this year and I'm a member

1 of that oral health initiative going state to
2 state to help states get up and running.
3 MEMBER LIEBERTHAL: But AAP is
4 recommending the fluoride varnish?
5 DR. DEINARD: AAP is recommending
6 the fluoride varnish, as does AAFP. They are
7 both referring to the ADA policy which now
8 says that varnish should be applied quarterly
9 to the teeth of high-risk children starting at
10 age one.
11 A high-risk child can be very
12 simply defined as a Medicaid child or a CHIP
13 child who does not have a dental home, i.e.,
14 a home where the child can go for dental care
15 whenever there's a problem and regardless of
16 what the problem is.
17 A lot of mothers will say, "I've
18 got a dentist," but that was to have one tooth
19 pulled and the dentist won't see the child
20 again. Biggest problem today is the dentists
21 generally don't want to see Medicaid or CHIP
22 children. They will turn their backs on them

1 unlike physicians who must.
2 If I don't want to take care of a
3 patient, I'm obligated to triage that patient
4 to somebody else. Dentists seem to have no
5 compunction whatsoever to turn their backs and
6 say, sorry, I don't take Medicaid. Good bye,
7 without any questions asked about triaging and
8 it's a national crisis. The opening words to
9 the Surgeon General's Conference in 2000 were
10 the mouth is part of the body and that was
11 echoed over and over again for three days.
12 CO-CHAIR HOMER: So I think, just
13 to stick to the process, outstanding content,
14 but just to stick to the process just in terms
15 of a vote on importance. All in favor of
16 saying this is sufficiently important to go
17 forward or meets the criteria completely, I
18 guess, is the question.
19 DR. WINKLER: Is Marlene still
20 with us?
21 MEMBER MILLER: I'm here. I vote
22 I guess completely.

1 DR. WINKLER: Okay, yes. All
2 right. Great. Thanks.
3 CO-CHAIR HOMER: So that is how
4 many for completely? Everybody. Okay. So we
5 will dispense with the other categories. All
6 right. Moving into the scientific
7 acceptability of the measure. David.
8 MEMBER CLARKE: I think everything
9 was pretty good with the science of it. I
10 didn't really come across any problems that I
11 had. I don't know if any of the other
12 reviewers did.
13 CO-CHAIR HOMER: I actually did
14 have a question somewhere between the
15 scientific and probably on the feasibility
16 side. You mentioned that the only exclusion
17 is if the child has a dental home and I
18 wondered how that could be obtained through
19 the kinds of data.
20 I saw a mismatch between basically
21 this could be easily collected in a valid,
22 reliable way from encounter data and you've

1 got this concept of the dental home which is
2 do you have access --
3 DR. DEINARD: The primary care of
4 prevention and intervention in my mind has
5 five pieces to it; a physician, family
6 medicine, pediatric, nurse practitioner,
7 physician assistant, public health nurse. In
8 Minnesota there are more EPSDT exams done in
9 greater Minnesota by public health nurses even
10 than by family medicine docs. They do a lot
11 of them.
12 So gross examination of the teeth,
13 eye balling. Not with a probe and x-rays as
14 the dentist uses but eye balling it. If it
15 looks like a train wreck, try to find a
16 dentist who will tell you either it's a
17 variant of normal or a train wreck. If it's
18 a train wreck, the dentist will hopefully fix
19 it.
20 The second is a risk assessment,
21 paper and pencil, 30 seconds. There are a
22 number of risk factors: the mother's oral

1 health status, the siblings' oral health
2 status, do they have a toothbrush, do they use
3 fluoridated water, fluoridated toothpaste,
4 etc.
5 But if the child is on Medicaid or
6 CHIP and has no dental home, that child is
7 high risk. If you're high risk, according to
8 the ADA recommendations, you should get the
9 varnish four times a year.
10 The third part of the intervention
11 is anticipatory guidance to the care giver
12 which is every bit as important as the varnish
13 in telling the care giver (a) the ideology of
14 caries and then (b) the care giver's role in
15 prevention of caries.
16 If the mother continues to (a)
17 lick the pacifier with her own saliva before
18 she puts it in the child's mouth, and I've
19 seen that 10,000 times if I've seen it once
20 when the sink is right at the mother's elbow
21 and she prefers her saliva, all she's doing is
22 moving strep mutans from her mouth to the

1 child.

2 Strep mutans is the principal

3 organism that metabolizes the sugars that come

4 in the bottles that the mother is feeding the

5 child all day and all night long. The bug

6 digest the sugars for its own metabolic

7 purposes.

8 Its excrement is acidic. The

9 acidic excrement etches the enamel of the

10 tooth and the caries process is started. The

11 mothers need to understand the dynamic here.

12 It's insufficient to say don't put the kid to

13 bed with a bottle. There's got to be an

14 explanation why not or the mother will pay no

15 attention. That's the third part.

16 The fourth part is putting the

17 varnish on four times a year. The fifth part,

18 according to the Academies of Pediatrics and

19 Pediatric Dentistry every child should have a

20 dental home by age one so you should still try

21 to find one even though you know full well

22 that it happens very infrequently.

1 That is one of my complaints about
2 the dental element of the EPSDT exam that CMS
3 has articulated. All you have to do is put in
4 the chart "made a referral to the dentist."
5 It will fail a hundred times but you'll pass
6 audit a hundred times and you've done nothing
7 for the child as a consequence of telling the
8 mother to find a dental home.
9 CO-CHAIR HOMER: I couldn't agree
10 with you more. You weren't here first thing
11 in the morning. Marlene Miller said we should
12 have a change package with every measure and
13 you've articulated the change package. But we
14 are voting on the measure so I need to know
15 more about --
16 DR. DEINARD: The measure is if
17 the child gets varnished, presumptively the
18 child is high risk, the Medicaid child. From
19 the claims data, at least in Minnesota, the
20 claims data I have a report that I get and now
21 I've gotten two reports, 2008 and 2009, that
22 shows the billing entity, either the clinic or

1 the doc.

2 It shows three columns: zero to

3 five years of age, six to 12, 13 to 20, but

4 that could be subdivided any which way. It

5 shows duplicated and unduplicated EPSDT exams

6 by provider type and duplicated and

7 unduplicated fluoride varnish application by

8 provider type.

9 This goes across the page so I can

10 see that Dr. X had three children who got an

11 EPSDT exam. He did eight in total on those

12 three children. He put varnish on one child

13 one time. That's the kind of report that I

14 can get from the state.

15 CO-CHAIR HOMER: So what is the

16 measure that you are proposing?

17 DR. DEINARD: The measure that I

18 would like to track is that physicians have a

19 primary role in caries prevention by virtue of

20 the fact that children can't get dental care.

21 Therefore, one way to try to prevent caries is

22 to put varnish on and presumptively along with

1 the varnish goes the education, etc.
2 Like anything else in pediatrics
3 we do anticipatory guidance on a whole range
4 of topics. We do risk assessments across the
5 board and we are always giving advice trying
6 to keep something from happening before it
7 happens.
8 CO-CHAIR HOMER: I'm trying to
9 help here. I want this measure -- I
10 personally sit on the board of an institute
11 that focuses on improving this kind of work.
12 I'm trying to help get a measure that we can
13 decide on its scientific merit and I need a
14 definition. I'm thinking not as an advocate
15 and not as a pediatrician who cares about
16 kids. I'm trying to think as a measurement
17 sort of person. Tell me what the numerator
18 is.
19 DR. DEINARD: The numerator is the
20 number of children who got varnish duplicated.
21 How many varnishings went on all the children
22 who had an EPSDT exam. The denominator is the

1 number of EPSDT exams done. If every child
2 gets a varnish every EPSDT visit, or at least
3 on a quarterly basis, then the number of
4 varnishes should equal the number of EPSDT
5 exams done.
6 CO-CHAIR HOMER: So the numerator
7 is the number of varnish applications?
8 DR. DEINARD: Yes.
9 CO-CHAIR HOMER: And the
10 denominator is the number of EPSDT
11 evaluations.
12 DR. DEINARD: Yes. Ideally it
13 should be one to one, every time a kid comes
14 in. Now, for the very young child who may
15 come in -- what was the question?
16 CO-CHAIR WEISS: Is it varnish
17 applications or is it children? What's the
18 numerator?
19 DR. DEINARD: The numerator is the
20 total -- well, you can look at it two ways.
21 The number of unduplicated children who had an
22 EPSDT exam is the denominator and the number

1 of those kids who got one or more varnishings.
2 CO-CHAIR HOMER: That's a
3 different measure.
4 DR. DEINARD: The other measure is
5 the total number of varnishes done as a
6 function of the total number of EPSDT exams
7 done.
8 CO-CHAIR HOMER: So, again, are
9 you recommending -- I don't mean to be
10 grilling and please forgive me.
11 DR. DEINARD: That's okay.
12 CO-CHAIR HOMER: This is a
13 developmental process for us as a committee
14 and I think for the people who are proposing
15 measures to us. What I hear actually are that
16 you are proposing two measures. One is the
17 number of varnish applications divided by the
18 number of EPSDT exams. The other is the
19 number of children who had one or more varnish
20 applications over the number of children who
21 had --
22 DR. DEINARD: Who had one or more

1 EPSDT exams. That's the unduplicated number.
2 CO-CHAIR HOMER: Okay.
3 MEMBER JENKINS: And where does
4 the concept of the dental home come in?
5 DR. DEINARD: Presumptively if a
6 child has a dental home and is seeing the
7 dentist twice a year because dentists get paid
8 for the procedures they do and not for just
9 doing an exam. You can be very certain that
10 that child got varnish at each visit.
11 MEMBER JENKINS: Would that be an
12 exclusion from the denominator or not?
13 DR. DEINARD: In a pediatric
14 practice if I have a patient who is seeing the
15 dentist regularly, mother says, I go to the
16 dentist twice a year, then they get varnish
17 twice a year. Fine.
18 I would say you're high risk. The
19 other two times a year I'll do the varnishing
20 because the dentist won't even get paid if he
21 does more than two. The physicians will get
22 paid, at least in Minnesota, for as many

1 applications as they want to do. Each state
2 is different in that regard.
3 CO-CHAIR HOMER: In Minnesota how
4 would you know to take those kids out of your
5 denominator right now or just you just sort of
6 say it's so small --
7 DR. DEINARD: I would say it is so
8 small and then I could also by virtue of the
9 number of kids who got an EPSDT exam go to the
10 database and ask how many dental visits did
11 you pay for this year? I mean, it's a very
12 small number. That's the problem. There are
13 too few dentists seeing all the kids that
14 carry the risk.
15 It's just a way of saying you
16 don't need it four times a year. If you've
17 got a home, get it at least twice a year at
18 the dentist and twice at the doc. But if most
19 of these kids don't have a dental home, you
20 get it four times a year at the doc.
21 CO-CHAIR WEISS: Given the
22 population that you've chosen to focus on,

1 Medicaid and CHIP, and the presumption that
2 very few of these children have a medical
3 home --
4 DR. DEINARD: Dental home.
5 CO-CHAIR WEISS: Excuse me, a
6 dental home, the two most important measures
7 here are the number of applications over the
8 EPSDT exam number and the number of children
9 over EPSDT exams. Correct?
10 DR. DEINARD: Yes.
11 CO-CHAIR WEISS: And then we are
12 working toward the idea of a dental home for
13 everybody.
14 DR. DEINARD: Yes, but it will be
15 a lot easier to get the docs to put varnish on
16 than wait for that dental home to arrive for
17 everybody. That's a long wait.
18 MEMBER LIEBERTHAL: I have a
19 question here. I don't know about Minnesota,
20 but in California EPSDT is not four times a
21 year. EPSDT exams occur once a year other
22 than for the children under two who follow the

1 AAP schedule.

2 Without questioning the value of

3 the fluoride varnish and the number of

4 fluoride varnishes that is ideal and just

5 looking at a measure that has to be clearly

6 defined, it would seem to me that if you are

7 correlating for a varnish with EPSDT exam,

8 that should be the measure with the numerator

9 being fluoride varnish and the denominator

10 being EPSDT exam.

11 DR. DEINARD: Unduplicated.

12 MEMBER LIEBERTHAL: What do you

13 mean by duplicated?

14 DR. DEINARD: If one child comes

15 in and gets the treatment once, it's one and

16 one, duplicated and unduplicated. If one

17 child comes in and gets it four times, it's

18 one child with four applications and the

19 duplicated part is the four.

20 MEMBER LIEBERTHAL: But if your

21 recommendation is four applications a year, I

22 don't see the value of using the duplicated or

1 unduplicated. The relationship is that --
2 again, it depends on the frequency of the
3 EPSDT exams, which in California is not four
4 times a year.
5 DR. DEINARD: You could also since
6 the children are coming in hopefully to an AAP
7 schedule that calls for a certain number of
8 well child exams over the first five years of
9 life, you could also take CPT code for the
10 well child exam as well as the CPT code for
11 the EPSDT exam.
12 MEMBER RAO: That was the question
13 I had. Why link it to EPSDT exams at all?
14 DR. DEINARD: Because when CMS
15 comes into audit they take a look at how many
16 EPSDT exams you do and have you met all 13
17 expectations of the EPSDT exam. In my view
18 having been trained in the dark ages an EPSDT
19 exam is another name for a well child exam
20 Yes, sir.
21 MEMBER McINERNY: However, in many
22 states, Medicaid children are not getting

1 EPSDT exams at the recommended intervals and
2 so you could have a Medicaid patient come in
3 who is at risk who does not get an EPSDT but
4 should have a varnish and, therefore, you've
5 missed that patient because you didn't count
6 that because they didn't have an EPSDT exam.
7 DR. DEINARD: What kind of
8 encounter are you proposing that child have,
9 just a well child exam?
10 MEMBER McINERNY: Well child exam.
11 DR. DEINARD: Okay. If that's the
12 case in that state, I would say look at the
13 number of well child plus EPSDT exams done and
14 lump the two together as the denominator.
15 MEMBER McINERNY: I would exclude
16 the EPSDT because they may not do the EPSDT
17 but they might put the varnish on.
18 DR. DEINARD: Okay.
19 MEMBER McINERNY: Furthermore,
20 they come in at a year of age, 15 months, 18
21 months, two years of age. The next one isn't
22 until age three.

1 CO-CHAIR HOMER: If I could
2 interrupt to take the Chair's prerogative,
3 this has been a very rich conversation where
4 we have learned a lot about issues around
5 varnish, EPSDT, etc. It seems clear to me in
6 the conversation that we don't actually have
7 a measure that is highly specified because,
8 again, as you said, we could define it this
9 way, we could define it that way.
10 We could have this numerator, we
11 could have that numerator. All of those may
12 be useful but we as a committee I would argue
13 my personal opinion that we actually don't
14 have a specified measure that we can discuss
15 and vote on so by this scientific
16 acceptability the first thing is there is
17 specifications.
18 I think we are not there yet.
19 Therefore, it becomes very challenging for us
20 to even make an assessment against the other
21 criteria of scientific acceptability such as
22 reliability, validity.

1 There is confusion here about
2 exclusions because we don't have a
3 consistently -- the idea with an NQF measure
4 is that you have a measure that is highly
5 specified so that not only in Minnesota but in
6 Rochester, New York or in Florida or
7 Washington State that you could take this
8 measure, follow the numerator, follow the
9 denominator, and come up with a comparable --
10 DR. DEINARD: But you're making an
11 assumption that every state behaves like every
12 other state. In Minnesota they do lots of
13 EPSDT exams. If in another state they fail to
14 code it as an EPSDT but code it as a well
15 child.
16 CO-CHAIR HOMER: Then we would
17 need to develop specifications, in my view.
18 Anyhow, that was my assessment and I said that
19 in part to see if we could accelerate or come
20 to some closure around this section of the
21 conversation.
22 Kathy.

1 MEMBER JENKINS: Charlie, I agree
2 with you and I'm also noticing, as Ellen is as
3 well, that it is, in fact, a process measure.
4 It might be an excellent process measure that
5 we could craft into that CHIPRA thing that we
6 talked about at the beginning which might be
7 a real value in the country for the CMS
8 population.
9 I would also note that
10 organizations like NACHRI can take help with
11 the gap here to craft a measure that might
12 work across the country. We could hold the
13 thought today but get a much better thought
14 before too long.
15 MEMBER McINERNY: That's a good
16 point. I mean, the outcome measure is the
17 number of children with caries who are on
18 Medicaid.
19 MEMBER JENKINS: I know that we've
20 tried with our dental group to craft a caries
21 measure. They are very difficult to do. They
22 may work at the population level but there is

1 another one that is not going to fold downward
2 but the process measure here is very, very
3 important.
4 CO-CHAIR WEISS: Let me also say
5 that for many years there have been problems
6 with the content of the EPSDT visits and so
7 while in Minnesota you appear to be very far
8 along in terms of the number of visits and so
9 on that are expected, it would not be a bad
10 idea to think about correlating a varnish with
11 an EPSDT visit just to be sure that the
12 varnish is, in fact, incorporated into that
13 treatment package.
14 DR. DEINARD: I would be perfectly
15 content to say that the denominator is a well
16 child exam. In Minnesota, I know I can get a
17 report of those who had well child exams and
18 those who had EPSDT exams. The question is,
19 state by state, no matter what kind of well
20 child care, you can put varnish on as part of
21 an ill child visit. It doesn't matter.
22 By the way, you start putting the

1 varnish on with the eruption of the first
2 tooth or by age one. Kids come in starting at
3 two weeks, two months, four months, six
4 months, nine months, 12 months so there are
5 lots of opportunities in that first year of
6 life to put varnish on at least at six and 12
7 months.
8 You can do it as part of an ill
9 child visit if you miss the child as part of
10 a well child visit. Or if the child fails the
11 well child and comes in ill and it's more than
12 four months since the last varnish you can put
13 it on.
14 You could take a look at your
15 varnishes as broken up in three ways: as a
16 function of well child care as a denominator,
17 as a function of ill child care because all
18 ill child visits have a code. The key thing
19 is that the code for varnish is a unique code,
20 D1206 in all the states but three and they are
21 using -- it's in the materials I presented, a
22 CPT code with a modifier.

1 Most of the states that are coming
2 on board now, by the way, come July 1 there
3 will be 37 states that are reimbursing, not
4 35. Progress is being made and Alaska and New
5 Hampshire are right on the edge of joining the
6 blue states.
7 You could set three different
8 denominators. The question is as part of
9 those encounters are the physicians doing what
10 they could and perhaps should be doing in the
11 way of oral healthcare for that child by
12 putting varnish on?
13 CO-CHAIR HOMER: I would say
14 Kathy's point though, one, this is a process
15 measure which means we should revisit it when
16 we are revisiting process measures. Number
17 two is I would say for us to truly consider
18 this as a process measure we will need more
19 detailed specifications and actually some
20 probably greater test data that says this
21 actually performed this way in these settings
22 so that we could actually get some experience.

1 That is where I'm thinking going
2 forward. Why don't we just follow the process
3 and keep Reva and Nicole happy by making sure
4 that we vote on the different criteria that we
5 need to do unless we want to just table it.
6 I guess that is another option.
7 DR. WINKLER: Or, Charlie, you
8 could kind of bypass this and basically say
9 that being it's a process measure it's sort of
10 out of scope for this but we really would like
11 to see a tighter specified version in the next
12 phase when we are really addressing the CHIPRA
13 measures. That is an option.
14 CO-CHAIR HOMER: I'm seeing a lot
15 of head shaking around the room. I would like
16 to make sure staff has the opportunity to
17 speak with our guests and make sure and maybe
18 give some examples of some other well worked
19 up process measures so that we can provide
20 help to make sure that this comes back in a
21 timely basis so we can consider it effectively
22 because it is one of the critical health needs

1 of children on Medicaid. Yes, Nancy?
2 MEMBER FISHER: Ideally in the
3 ideal world what would you want to see about
4 varnish?
5 DR. DEINARD: In an ideal world
6 for the Medicaid CHIP child?
7 MEMBER FISHER: For anybody.
8 DR. DEINARD: Well, for those who
9 can get -- if you take a look today at the
10 caries, who has caries today? 30 percent of
11 children. Who are those 30 percent? The
12 Medicaid CHIP kids.
13 Mexican-Americans have more
14 disease than the African-Americans who have
15 more disease than the Caucasians and the
16 Africans and the Southeast Asians and the
17 American Indians close to somewhere between
18 the Mexican-Americans and the African-
19 Americans. I would like to see medical
20 providers be putting varnish on according to
21 the ADA recommendation four times a year for
22 those populations.

1 MEMBER FISHER: Okay. What I'm
2 trying to get at is, in an ideal situation we
3 have standards, like for immunizations you get
4 so many immunizations. You are trying to do
5 it by a certain time. What I'm saying is that
6 ideally would you like all kids that they have
7 no fluoride in the water or something is to
8 get fluoride varnishes before the age of two?
9 DR. DEINARD: Starting at six
10 months or the eruption of the first tooth.
11 MEMBER FISHER: Okay. I'm just
12 trying to give some space for, you know,
13 you've got time to get it in there. Would a
14 goal be to start out I would like to make sure
15 all kids have four by the age of two, by the
16 age of 18 months? Something that was
17 realistic. It could be done and it gets us on
18 our way.
19 DR. DEINARD: I would like to see
20 every child get four in the first year of life
21 starting with age one to age two, another four
22 between age two and age three, and all the way

1 up to age 20 because teenagers are rotting
2 their teeth out drinking Coke all day long.
3 MEMBER FISHER: I understand that
4 but I'm saying that we've got immunization
5 things and we know we aren't getting some of
6 them until they are teenagers. I just want to
7 get a specific goal. If you tell me you want
8 two by the age of -- what did you say -- two
9 or four or something like that?
10 DR. DEINARD: I think four by the
11 age of two on those who are high risk.
12 Immunizations go to all children. This is for
13 the high risk kids who don't have dental care.
14 CO-CHAIR HOMER: So just to wrap
15 up the conversation, I do think if you think
16 of the immunization measures, a great example,
17 children across the country have to meet the
18 same immunization standards regardless of
19 whether you have a lot of EPSDT or you don't
20 have a lot of EPSDT or whatever it is.
21 As we are reworking this measure,
22 as we are working with staff on this, we want

1 to come up with criteria so that there is a
2 universal measure against the universal
3 standard that would apply in every state
4 because that is really where our charge, NQF's
5 charge, and also the CHIPRA legislation is
6 moving to having standard consistent
7 measurement across states so that we can
8 compare performance and make sure that kids in
9 Minnesota are not the only children in the
10 country protected against dental caries. I
11 guess I would propose that wrap-up.
12 DR. DEINARD: If what you want to
13 do is table this today, that is perfectly fine
14 by me because I can see this is not going
15 where I was hoping it would go; namely, that
16 you would say this is really good stuff and
17 it's important because NCQA will pick up on it
18 and CMS will pick up on it and there will be
19 something going forward.
20 CO-CHAIR HOMER: I don't want you
21 to get --
22 DR. DEINARD: To go two, three,

1 four years on process is two, three, four
2 years with kids not getting what they should
3 be getting.
4 CO-CHAIR HOMER: No, I don't want
5 you to get the message that we don't think
6 this is critically important because we do.
7 I think there is a lot of excitement around
8 the room about the importance of this and
9 there is the belief that -- our committee is
10 going to be calling for process measures and
11 reviewing them or seeing them in July so we
12 are not talking like six years from now.
13 We are talking about a couple
14 months from now, but you actually have a fair
15 amount of work to do to develop greater
16 specifications for this for it to be able to
17 pass. I mean, it doesn't go from our mouth to
18 God's ear.
19 It's got to go through additional
20 levels of review and commentary so it's really
21 friendly advice to come back with something
22 that we know is going to be able to pass

1 muster because this is an important topic that
2 we want to see.
3 DR. DEINARD: What concerns me is
4 that when you start looking at how states
5 differ, why should that be any less important
6 when you look at process, which is what we are
7 looking at here today. Someone will say you
8 do it this way in this state and this way in
9 another state and we can't compare apples and
10 oranges. There is no comparability.
11 CO-CHAIR HOMER: You could define
12 encounters for either well child or EPSDT in
13 such a way or you could say all children by
14 the -- we can talk offline. This isn't the
15 committee in which we should actually develop
16 the measure.
17 MEMBER FISHER: Can I just make
18 one more comment? The reason why I asked for
19 something that was standard for all kids is
20 I'm thinking about the practitioner who is out
21 there. It's much easier to keep it simple.
22 I mean, I can't memorize now all

1 the immunizations but when I was really doing
2 them I knew them and I didn't look at somebody
3 whether they're poor or rich or Medicaid. You
4 got an immunization, you know, so that's all
5 I'm trying to do is keep it simple, get it
6 into the practitioner's head you need this and
7 you get it by a certain time.
8 DR. DEINARD: The difference --
9 MEMBER FISHER: And just because
10 you're rich doesn't mean that you don't get
11 cavities. It just means you can have them
12 filled.
13 DR. DEINARD: The difference is
14 that all medical insurance will pay for
15 immunizations across the full socioeconomic
16 spectrum. Medical insurance today will not
17 pay for this on the commercial side. This is
18 only the Medicaid program in 37 states that
19 said they will pay. The others are still in
20 the works.
21 If you have a lot of kids who are
22 commercially insured on the medical and you do

1 this and you bill the medical side, you're
2 going to get denied and then you are going to
3 have a lot of angry parents saying, you didn't
4 tell me this was going to cost me money and
5 not covered by my insurance.
6 Offer it to them and charge them
7 for what you charge Medicaid because you would
8 like to offer one thing to everybody. For the
9 medically insured you offered it at a price
10 that the mother pays or doesn't pay.
11 To say we are going to give it to
12 every kid, you are going to have bedlam in the
13 offices where you've got 50 percent of the
14 commercially insured and Medicaid insured.
15 There is going to be a lot of bills and
16 charges unpaid and parents will be very
17 unhappy.
18 MEMBER FISHER: Some places people
19 have dental insurance and then I think the
20 other thing is that we get a standard and we
21 have to think of how we can get that paid.
22 Anyway, that's all I have to say.

1 DR. DEINARD: Dental insurance
2 will not reimburse the physicians because they
3 are not credential with the dental insurers.
4 MEMBER LIEBERTHAL: At risk of
5 prolonging the conversation that's not the
6 direct topic of this meeting, I think you are
7 aware of the implications of what you are
8 saying, four varnishes a year for all children
9 has huge implications with regard to frequency
10 of visits and cost of medical care that have
11 to be addressed.
12 That really isn't the province of
13 this committee. As you formulate this I think
14 you have to be very aware that a combination
15 of four visits a year to a dentist and to a
16 physician is not the standard of care.
17 DR. DEINARD: Well, from the
18 medical side when you get over age two and
19 children only come in for well child care once
20 a year, just like you run immunization clinics
21 you can run fluoride varnish clinics. The CMA
22 puts it on and you're out the door.

1 CO-CHAIR HOMER: Any last
2 comments?
3 MEMBER PERSAUD: Just two last
4 comments. One place you might look at when
5 you are looking at the states I think part of
6 the opportunity here is to come up with some
7 reasonable standard that would influence
8 practice, or rather best practice in states
9 and performance of Medicaid and CHIP systems
10 in paying for things that are going to be
11 ultimately effective.
12 You might look at Texas. We are
13 rarely ahead on anything but as of two years
14 ago we began making the referrals to dental
15 homes at six months and started varnishing at
16 nine months either by us or by the community
17 dentist.
18 I believe that the rate of
19 children reaching the dentist for the first
20 time between one and two years of life has
21 proportionately increased since we did that.
22 I think there are opportunities here for you

1 in developing the measure to come up with what
2 should guide best practice.
3 CO-CHAIR HOMER: Any other
4 comments? Okay. Kathy.
5 MEMBER JENKINS: A process
6 question, Charlie. It seems obvious to me
7 that -- I'm sorry. I don't know your name but
8 in order to meet the standard of the process
9 application in July could use a little help.
10 How does that work? Who is going to help?
11 MS. McELVEEN: It would
12 essentially be staff, of course, guided by you
13 all if you have specific recommendations that
14 you can provide to him that we can then work
15 with him to do. You have identified some of
16 those here throughout your discussions today.
17 CO-CHAIR HOMER: Thank you very
18 much. I know this was not the result you
19 wanted but I think we will end up where you
20 want to be.
21 DR. DEINARD: Well, I hope you're
22 right.

1 CO-CHAIR HOMER: So let's move on
2 to the next measure on our list and we are
3 going to go back to -- oh, is there a public
4 comment?
5 MS. McELVEEN: We usually allow
6 the audience to come up but we don't have any
7 audience.
8 CO-CHAIR HOMER: Okay.
9 MS. McELVEEN: I wanted to get
10 feedback from the group. The next measure
11 that is up for discussion is that larger
12 survey measure that has 22 individual measures
13 comprised within it.
14 I think based on our previous
15 conversations it would probably be safe to say
16 to table that for now and maybe look at the
17 individual components first. Are there any
18 objections to doing it that way or does anyone
19 have any further comments?
20 CO-CHAIR HOMER: Sounds like a
21 good idea.
22 MS. McELVEEN: Okay. So that

1 takes us to -- sorry. Let me just pull up the
2 table here. This is Work Group 3 and the
3 measure we will be discussing first is 32.
4 Measure 32 again was part of a
5 larger survey measure. This single measure is
6 the number of school days missed due to
7 illness and the description measures the
8 quantitative number of days of school missed
9 due to illness or condition among children and
10 adolescents age 6 to 17 years of age. We
11 should probably start with an importance
12 discussion as we have been doing with all of
13 our measures.
14 CO-CHAIR HOMER: So anything from
15 on the Work Group 3?
16 MS. McELVEEN: Unfortunately we
17 only have two of the members who were assigned
18 to this work group present with us today.
19 CO-CHAIR HOMER: Allan?
20 MEMBER JENKINS: This is a measure
21 from the other major survey, the National
22 Survey of Children's Health. We alluded to it

1 this morning. This is one question on the
2 survey, the number of school days missed.
3 In terms of the importance, this
4 is widely regarded, I believe, as a very
5 important outcome measure that rolls up a lot
6 of aspects of child health. It's a relatively
7 simple measure. It's done by asking the
8 parent how many school days were missed over
9 the last 12 months due to illness or
10 condition.
11 I thought it passed the importance
12 criteria. There is also some data in the
13 application about the gap and variation,
14 although if I remember correctly, that was
15 presented as more than two weeks of school
16 missed.
17 Allan, I don't know what else you
18 would like to say to introduce this in terms
19 of an importance discussion.
20 MEMBER LIEBERTHAL: I agree with
21 you completely on importance. I had some
22 issues with it regarding some of the other

1 criteria but it certainly is an important
2 measure of public health.
3 CO-CHAIR HOMER: Any other
4 discussion about the importance?
5 CO-CHAIR WEISS: Charlie tells me
6 that researchers use this measure. I would
7 just like to know a little bit more. Who
8 looks at this and how is it used?
9 MEMBER JENKINS: I can tell you
10 that we're using it at the Children's Hospital
11 in Boston as a measure of effectiveness as an
12 asthma community health program and that all
13 of the process measures of asthma care every
14 time we discuss them people reminded everyone
15 that they were process measures and not
16 outcome measures and this was the one that
17 always rises to the top as the outcome measure
18 of interest.
19 If we could reduce the number of
20 school days missed from our asthma community
21 health program that we would be making a
22 difference in the asthma population.

1 MEMBER LIEBERTHAL: We use that,
2 too. I believe NHLBI in their impairment part
3 of the NHLBI guidelines includes days of
4 school missed and function when they are not
5 having an acute exacerbation.
6 Also in my general practice when
7 I'm dealing with kids with a variety of
8 illnesses, and especially children who have
9 what turn out to be psychosomatic illness such
10 as frequent headaches, frequent abdominal
11 pains.
12 One of the important questions I
13 ask is how many days of school are you missing
14 because that may give me some idea of how much
15 impact these symptoms are having on the
16 child's health.
17 CO-CHAIR WEISS: But in both cases
18 you're relating school days missed to a
19 particular condition or a particular
20 diagnosis. Right? Is that picked up in this
21 measure? I don't think that it is.
22 MEMBER LIEBERTHAL: No. That's

1 one of the problems is we get to scientific
2 acceptability, usability, and feasibility.
3 CO-CHAIR WEISS: Okay.
4 CO-CHAIR HOMER: So, again, just
5 from the process perspective does it meet the
6 threshold for importance criteria? All those
7 who feel it completely meets the criteria,
8 please raise your hand.
9 DR. WINKLER: Marlene?
10 MEMBER MILLER: Yes.
11 DR. WINKLER: Thank you.
12 CO-CHAIR HOMER: That's everybody.
13 Okay. Now, moving onto the scientific
14 acceptability.
15 MEMBER LIEBERTHAL: I can speak to
16 that. It's a very imprecise question. The
17 way it's phrased it just uses the term illness
18 or injury and parents have different
19 interpretation.
20 Also, many parents will keep a
21 child home from school for their own personal
22 convenience or for other reasons but they

1 attribute it to illness because it's more
2 socially acceptable, just as many of our
3 workers attribute their personal days off to
4 illness.
5 Also, if you ask a parent, and I
6 run into this a lot, if you extend it to how
7 many days a child has missed in the past year,
8 they are going to most likely generalize it
9 from their most recent experience just as when
10 they say, they are always sick. When you come
11 down on it they have been sick every other
12 month, not always sick.
13 If I get a child, again with
14 asthma, he might have missed a week of school.
15 Then I asked them how many days did he miss in
16 a year. They either don't know or they guess
17 based on the fact that he just missed a week
18 so it really doesn't differentiate.
19 Also there is no differentiation
20 of healthy children from children with special
21 health care needs. I think there are a lot of
22 problems that it is such a generalized

1 question.

2 MEMBER JENKINS: I agree. I had

3 the same thought about the scientific issues

4 associated with it. They did a good job with

5 excluding children who were home schooled and

6 that sort of thing. Exclusions were pretty

7 well specified.

8 I thought they did actually

9 stratify or exclude patients with special

10 health care needs but, again, it's based on

11 essentially a mother's recollection and

12 writing down a number over an entire year and

13 I thought there was very likely to be

14 respondent bias in that.

15 Interestingly it is a measure that

16 can be validated. The community medicine

17 program I was alluding to earlier they

18 actually use school records to count school

19 days missed as opposed to mother's

20 recollection of school days missed. It's not

21 one of those where it's impossible to actually

22 count school days missed from a different

1 source.
2 MEMBER McINERNY: That was my
3 question. Have people looked at the parents
4 said the child missed six days of school in a
5 year and then they go to that child's school
6 record and find out they missed 3 days of
7 school or they missed 12 days? Is there good
8 correlation?
9 MEMBER JENKINS: There's no
10 validity presented by the measure.
11 MEMBER ZIMA: School record data
12 is complicated. I'm just going to say one
13 thing and then say we won't go there. That is
14 that you also have variation by the length of
15 time a child's semester is and grading period
16 and sort of picking what semester or grading
17 period you are going to do and then adjusting
18 it to the number of days for that grading
19 period is a lot of work so that's one issue.
20 Then the other, I've got a
21 question. I'm not sure because I'm concerned
22 with the denominator including the word or

1 injury. I was wondering whether those around
2 the table who have thought about this thought
3 about having handled that part of the
4 numerator.
5 MEMBER DOCHERTY: I just wanted to
6 respond to the question about whether or not
7 parents can report the number of school days
8 missed. I general in research literature with
9 chronically ill or children with special
10 health care needs, parents are actually found
11 to be very reliable reporters of the numbers
12 of days.
13 I can't think of any citations off
14 the top of my head but we know that parents,
15 especially mothers, are very good at being
16 able to recollection symptoms, number of
17 symptoms, and the variety of repercussions of
18 the symptoms of their children's chronic
19 illnesses.
20 While there is absolutely no
21 perfect measure of this kind of thing,
22 obviously the school records are difficult to

1 get, I feel that mothers are pretty reliable
2 in terms of if you ask them to think back
3 specifically over the last month, and then the
4 preceding seasons were they any worse than
5 this past season, that they actually are
6 pretty reliable reporters of their sick
7 children.
8 I don't know about healthy
9 children. This is just research with
10 chronically ill children or children with
11 special health care needs.
12 CO-CHAIR HOMER: I guess I also,
13 again, when I looked at this literature in the
14 past and I wish, again, more information was
15 presented, one of the challenges in using
16 something like school records and one of the
17 reasons that having the illness or injury
18 question is useful is that really as, Allan,
19 you suggested, the major determinant of school
20 attendance has much more to do with maternal
21 functioning than it does with child health.
22 Obviously those two are not

1 unrelated. Twenty or thirty years ago Michael
2 Weitzman did a series of studies looking at
3 the utility of school days missed as an
4 indicator of asthma performance and found that
5 just using it on a global basis it was
6 overwhelmed, at least at that point, by other
7 measures of social dysfunction compared to
8 illness management. I think that is why due
9 to illness or injury sort of comes in there
10 rather than just leaving it as a straight
11 count.
12 And then I think -- I guess this
13 is a legitimate question. If one is trying to
14 develop an indicator that you are going to be
15 able to use in multiple places in a feasible
16 low cost way and somebody is doing the survey
17 on a regular basis, it's not a bad way to go.
18 Again, maybe that's more on the
19 feasibility than the validity because there is
20 definitely a trade off that you do remember
21 things better more recent obviously. I love
22 the way you did that sequential questioning of

1 last season but it doesn't look like that is
2 how they -- is that how they asked the
3 question?
4 MEMBER JENKINS: It's consistent
5 across the whole survey using 12 months.
6 Presuming that the respondent was in the mind
7 frame of the survey it's consistent throughout
8 all the questions.
9 CO-CHAIR HOMER: Any comment on
10 any of the other elements of scientific
11 acceptability that are worthy of note? Risk
12 adjustment is not appropriate. There are
13 differences that they reported.
14 DR. WINKLER: Just to clarify, you
15 said risk adjustment is not appropriate?
16 CO-CHAIR HOMER: I was just
17 looking at the scores that are up on the
18 board.
19 DR. WINKLER: This just said that
20 it doesn't meet the criteria.
21 CO-CHAIR HOMER: Oh, I'm sorry.
22 Thank you. I had a misplaced column there.

1 MEMBER JENKINS: I think it's back
2 to that comment we made at the very beginning
3 where across the entire country, across the
4 entire survey with a percentage of patients
5 with special health care needs missing school
6 be different in various states or geographic
7 regions. It's a potential confounder that may
8 not be especially serious to understanding
9 variation.
10 MS. McELVEEN: Just a
11 clarification. This particular survey is not
12 a component of the one for children with
13 special health care needs.
14 CO-CHAIR HOMER: This is ultra.
15 MEMBER JENKINS: Right, it's
16 ultra. I just wanted to make that
17 clarification.
18 CO-CHAIR HOMER: Do you know if
19 this survey includes the screener, though?
20 Can you stratify? I would have to look and
21 see and I'm not sure that's critical to
22 answering this question. I thought it did.

1 All right. So can I have a vote on those who
2 feel it completely meets the criteria for
3 scientific acceptability?
4 Marlene?
5 MEMBER MILLER: Does not.
6 CO-CHAIR HOMER: Okay. Partially
7 meets the criteria?
8 DR. WINKLER: One, two, three,
9 four, five, six, seven, eight, nine, and
10 Marina is not here. Okay.
11 CO-CHAIR HOMER: So we'll get her
12 when she comes in. Good.
13 DR. WINKLER: I think you need to
14 put minimally.
15 CO-CHAIR HOMER: Minimally.
16 DR. WINKLER: One, two, three,
17 four.
18 MEMBER MILLER: I say minimally.
19 DR. WINKLER: Okay. That's five
20 for minimally with Marlene.
21 CO-CHAIR HOMER: And not at all?
22 Did you get everyone already?

1 DR. WINKLER: I think so with the
2 exception of Marina. You're partially,
3 minimally, not at all?
4 CO-CHAIR WEISS: Partially.
5 DR. WINKLER: Partially. Okay.
6 So that makes that a 10.
7 CO-CHAIR HOMER: All right. Let's
8 move on then to the usability section.
9 MEMBER LIEBERTHAL: I just don't
10 see what you are going to get out of this for
11 improving care. Not because it's not an
12 interesting number and not because it's not an
13 important number. It's just that the measure
14 is too broad to take any action based on it.
15 You have to really subdivide it as to causes
16 for school absence.
17 CO-CHAIR HOMER: Any other
18 discussion of that?
19 MEMBER PARTRIDGE: I just want to
20 say 100 percent agreement. I'm looking at
21 this really from the perspective if I said to
22 the parents in my community, we have a very

1 high rate of absenteeism in our school, the
2 next question they would ask is, why? Do we
3 have an epidemic of measles? What is it?
4 I would love a measure that was
5 more specific to certain conditions. I would
6 love a measure of a child that we think is
7 being treated for asthma, that dimension.
8 That would be a wonderful outcome measure but
9 this is too broad.
10 CO-CHAIR HOMER: But didn't we --
11 I mean, we actually specifically put this on
12 our list of things. We said we wanted
13 measures of global outcomes including broad
14 measures such as school attendance and we got
15 what we asked for.
16 MEMBER JENKINS: This isn't a
17 population-based measure. It's a very, very
18 high-level look.
19 MEMBER PERSAUD: I'm thinking
20 about things like during the flu season you
21 may have huge absences but what that's going
22 to reflect is that your threshold number of

1 children that you are immunizing in schools is
2 not high enough and you need to do something
3 about that.
4 I think it's a population measure
5 and I think as a population measure it can be
6 useful. It's not useful to the individual
7 level or for a clinic performance but I think
8 from a resource perspective and managing that
9 population in a community, I think it is a
10 useful measure.
11 MEMBER LIEBERTHAL: But you're
12 addressing a specific time period. This is a
13 12-month measure so the fact that there is
14 high absenteeism during the flu season could
15 not be identified by this measure.
16 I agree that this measure if it
17 were worded differently and not as broad would
18 be excellent. In response to Charlie maybe we
19 asked the wrong question.
20 CO-CHAIR WEISS: Let me just say
21 that I'm not sure I'm convinced that as a
22 population measure it's all that useful but,

1 you know, maybe I'm not thinking broadly
2 enough. However, it strikes me that the
3 providers of care, the clinicians who are
4 sitting around this table, are almost to a
5 person saying it is useful.
6 Sharon's point about parents who
7 deal with a chronically ill child using it as
8 a marker for how well their child's disease or
9 condition is being controlled is very
10 convincing to me that this is a useful measure
11 even if it doesn't have utility for the mayor
12 or the health commissioner generally.
13 MEMBER PARTRIDGE: I think I would
14 feel differently if you said the class we're
15 defining is children with special health care
16 needs. That narrows it enough for me to make
17 me feel that it has some usability. I'm not
18 making Charlie happy.
19 CO-CHAIR HOMER: Well, because I'm
20 doing queries right now and I can actually
21 query right now for kids who have a medical
22 home or don't have a medical home in Michigan

1 compared to Minnesota the number of days that
2 they are missing school. If I were a state
3 policy maker or whether you have a medical
4 home or not, you have given me some useful --
5 MEMBER PARTRIDGE: You've linked
6 it to a medical home.
7 MEMBER JENKINS: That's how people
8 would use it. If they found they were high on
9 this measure, they would then ask why and then
10 they would fall into various interesting
11 reasons why they were high on this measure.
12 CO-CHAIR WEISS: But as a stand-
13 alone measure it really isn't telling us a
14 whole lot at the general population level.
15 MEMBER DOCHERTY: It can be used
16 in statistical models with other variables to
17 explain more about what it's more predictive
18 of or what it's associated with other
19 variables so collect as a stand-alone measure
20 but then compared with other measure of that
21 population it could tell you more.
22 CO-CHAIR WEISS: Don't get me

1 wrong. I'm going to vote for this. I'm going
2 to vote for it because I think it does have
3 utility but in and of itself as a stand-alone
4 measure I honestly don't think that it tells
5 us very much that can be used on a population-
6 wide basis.
7 However, as compared to other
8 measures, the medical home being a perfect
9 example, and its utility for the practitioner,
10 and also with a parent with a child whose
11 function is being measured in part by how well
12 they are able to meet the scholastic kinds of
13 expectations, to me it has value.
14 CO-CHAIR HOMER: Nancy.
15 MEMBER FISHER: I was going to
16 say, though, when we talk about taking a
17 measure and looking at it at a higher level,
18 we already have that affirmation. It was
19 given to us in the evaluation of the measure
20 telling us how many kids with chronic disease,
21 I mean with special health care needs and
22 stuff. To me we have it at a higher level.

1 What we need is the measure that
2 goes down deeper to tell us specifically.
3 Like someone said, I don't know if you call it
4 healthy kids but you would have something on
5 kids with special health care needs, something
6 on kids with chronic disease if we don't have
7 that, and then the others that are supposed to
8 be normal or whatever, average I guess you
9 would say.
10 And then the kids with chronic
11 disease what you'd want to know is which
12 diseases and how it's keeping them out of
13 school. That to me would be more helpful.
14 Right now I think we have the information on
15 a higher level. That's where they are
16 justifying this measure.
17 CO-CHAIR HOMER: So help me with
18 this. Yes, this measure is already available
19 and you can query it on the website.
20 MEMBER FISHER: Yes.
21 CO-CHAIR HOMER: But I thought
22 that basically NQF needs to certify or as CMS

1 going forward is going to say if you want to
2 use this measure, for example, within your
3 state for a variety of purposes; quality,
4 measurement, and recording, it needs to be an
5 NQF endorsed measure.
6 MEMBER FISHER: Okay.
7 CO-CHAIR HOMER: Even if we have
8 it now and it's available and you say you want
9 to use it or the secretary says she wants to
10 use this when she's setting up comparisons or
11 things that are around the national report
12 card of how Washington State is doing compared
13 to Oregon, it would need to be NQF endorsed.
14 MEMBER FISHER: Okay. That's
15 different.
16 CO-CHAIR HOMER: Okay. So now
17 that we've --
18 MEMBER JENKINS: Feasibility, I
19 think. Right? Oh, we're going to vote.
20 CO-CHAIR HOMER: So let's vote on
21 usability. Is it understandable, is it
22 harmonized, and does it provide added value

1 basically over other things that NQF has
2 already endorsed presumably.
3 DR. WINKLER: We haven't done
4 anything like this
5 CO-CHAIR HOMER: There are no
6 measures then?
7 DR. WINKLER: Nada.
8 CO-CHAIR HOMER: So how many folks
9 feel this completely meets the criteria for
10 usability? Shockingly enough. Okay, one.
11 See, I didn't succumb to peer pressure.
12 Partially?
13 DR. WINKLER: Marlene?
14 MEMBER MILLER: I'm stuck between
15 partially and minimally.
16 DR. WINKLER: Okay.
17 CO-CHAIR HOMER: And then
18 minimally?
19 DR. WINKLER: Have you decided,
20 Marlene?
21 MEMBER MILLER: I'll go minimal.
22 DR. WINKLER: Okay.

1 CO-CHAIR HOMER: We balanced each
2 other out.
3 DR. WINKLER: Is there a not at
4 all?
5 CO-CHAIR HOMER: Okay. Good. Did
6 we catch everybody?
7 DR. WINKLER: Yes.
8 CO-CHAIR HOMER: Good. Then
9 feasibility.
10 MEMBER JENKINS: In terms of
11 feasibility this is coming from the national
12 survey and as long as there is still money
13 available to do the national survey, I guess
14 it's feasible to cut the data this way.
15 DR. WINKLER: I have one question.
16 How often is this survey administered?
17 MEMBER JENKINS: I think one was
18 every year and the other one was every four
19 years. Did I get that right?
20 CO-CHAIR HOMER: I'm not sure.
21 MS. McELVEEN: Yes, we can hear
22 you.

1 MR. STUMBO: Hi. Okay, sorry.
2 I've been listening. This is Scott Stumbo.
3 I work with Dr. Bethell. I've been on the
4 call for about a half hour. I just hadn't
5 been able to chime in yet. I wanted you guys
6 to know that I'm here.
7 This particular survey is
8 currently conducted every four years and it
9 alternates every two years with the national
10 survey of children with cavities.
11 CO-CHAIR HOMER: Which does make
12 it not ideal from a performance measurement
13 stand. It's kind of hard to track change.
14 MEMBER LIEBERTHAL: The only thing
15 on feasibility is the inaccuracies. I just
16 think that the data that you are going to get
17 from the parent report is inaccurate,
18 understanding that children with special
19 health care needs may be accurate but I think
20 for healthy children it's inaccurate. I mean,
21 feasibility is being done so I guess that's
22 okay but sometimes garbage in --

1 CO-CHAIR HOMER: Garbage out?
2 MEMBER LIEBERTHAL: I didn't say
3 that. I didn't say the second half.
4 CO-CHAIR HOMER: Okay. So why
5 don't we vote on the feasibility and then
6 we'll vote on the overall measure. How many
7 votes that this completely meets feasibility
8 criteria? I see none.
9 Marlene.
10 MEMBER MILLER: No, I wouldn't say
11 completely.
12 CO-CHAIR HOMER: Okay. Partially?
13 MEMBER MILLER: Partially.
14 DR. WINKLER: Fourteen.
15 CO-CHAIR HOMER: Minimally? One.
16 Okay. Good. All right. So time to call an
17 overall vote and that's just yes or no, right?
18 That's just recommend or not recommend. So
19 would we recommend moving this forward and
20 endorsing this as a measure? All in favor of
21 recommending the measure. This one is going
22 to be tight

1 DR. WINKLER: Twelve. Marlene?

2 MEMBER MILLER: No, I wouldn't.

3 CO-CHAIR HOMER: Nos?

4 DR. WINKLER: One here.

5 CO-CHAIR HOMER: Okay. The
6 measure carries.

7 MEMBER PARTRIDGE: Could we
8 consider a recommendation? It's not a
9 condition.

10 CO-CHAIR HOMER: Of course.

11 MEMBER PARTRIDGE: The discovery
12 that this is a survey every four years is a
13 little daunting and I wonder if we could
14 recommend the measure steward look at the
15 possibility of this data being gathered other
16 than through that survey. In other words, is
17 it feasible to incorporate something else that
18 is done more frequently. It would just be
19 useful to know.

20 CO-CHAIR HOMER: Sure. Good.
21 That would be great. Okay. That was very
22 productive. Where do we go next?

1 PARTICIPANT: Thirty-six.
2 CO-CHAIR HOMER: Another
3 straightforward one. Okay.
4 MEMBER McINERNY: I just want to
5 answer Lee's question. Certainly school
6 districts report absentee rates to the state.
7 Of course, I don't know why but we don't know
8 exactly why either.
9 MEMBER PARTRIDGE: Actually, this
10 crosses over into something we haven't talked
11 about much today at all. Where you have these
12 growing health information exchange exercises
13 there are certainly conversations going on
14 about the extent to which some of the data
15 that comes from schools can be shared through
16 that medium. It comes up often in the context
17 of health. That was part of my reason for
18 thinking we might explore more frequently.
19 CO-CHAIR HOMER: And the process
20 would be if someone came forward with that
21 kind of a measure going forward, then we would
22 go through some harmonization process at NQF

1 to choose which was the better strategy to go
2 forward.
3 Okay. So let's move on to measure
4 36, children who have no problems obtaining
5 referrals when needed. Could we hear from the
6 committee.
7 MEMBER LIEBERTHAL: I was on it.
8 You have to define needed versus wanted.
9 Again, this is parent opinion but an example
10 that I put in my comments -- well, if we are
11 just discussing importance, yes, I think it's
12 important that referrals be available, but
13 when we get down to the scientific and
14 usability, I think there are problems again.
15 I'll keep my comments at this point to just
16 yes, it's important.
17 CO-CHAIR HOMER: Any further
18 discussion since this is important? Good.
19 Are there disparities? Yes, there is a fairly
20 broad range it looks like, 9 percent in
21 Vermont to 29 percent in DC. Okay. Should we
22 have a vote?

1 MEMBER SCHWALENSTOCKER: Charlie,
2 I don't know if this comes here or not but I
3 guess I could use some input on how outcome-y
4 this is versus process-y and it's a tough one
5 and I just wonder what your's and other's
6 thoughts are.
7 MEMBER JENKINS: This was one of
8 the ones I was alluding to at the very
9 beginning with my questions, Charlie, about I
10 just scored it at face value but you said that
11 you hit it on the importance criteria.
12 CO-CHAIR HOMER: Yes, and how
13 close. I also think this is one that is on
14 the cusp. It's certainly an outcome of having
15 an effective system; that is, if you have
16 referrals readily available but it's not a
17 health status measure. It's a system
18 performance measure. Would you consider this
19 a system outcome measure; that is a reasonable
20 measure of whether you have an effective
21 system of mental health?
22 MEMBER ZIMA: Yes, particularly

1 for carved-out mental health for kids in
2 Medicaid. It would be an indicator of the
3 need to redesign the system and it will raise
4 a lot of questions about integrating
5 pediatrics and psychiatry together.
6 CO-CHAIR HOMER: Nancy.
7 MEMBER FISHER: When you do it
8 that way, what you are really looking at is
9 the kids that aren't getting the referrals.
10 That's what you're interested in. If you say
11 how easy is it to get a referral and so one
12 person gets a referral, you're not worried
13 about that person.
14 You're worried about the 99,000
15 other ones that didn't get a referral so to me
16 this isn't as important to me as the other
17 side of it because then you get that data and
18 then you have to drill down on it.
19 CO-CHAIR HOMER: The data that
20 they reported here are 20 percent of children
21 with special health care needs had problems
22 obtaining referrals so that is how they -- the

1 question is asked in the positive but --
2 MEMBER FISHER: They are answering
3 it the way that I want the answer.
4 CO-CHAIR HOMER: Exactly.
5 MEMBER FISHER: Yes. They are
6 asking one question and answering yet another
7 so that's what I said what --
8 CO-CHAIR HOMER: It depends. It's
9 actually at the response categories in the
10 instrument.
11 MEMBER FISHER: You said 20
12 percent of kids aren't getting it. Right? Is
13 that what you said?
14 CO-CHAIR HOMER: Yes, children
15 with special health care needs.
16 MEMBER FISHER: Okay. So 80
17 percent are getting it.
18 MEMBER LIEBERTHAL: This is a
19 general -- the denominator is all patients who
20 need referrals whether they have special
21 health care needs or not. The problem with
22 this one in the denominator is how do you

1 define needing a referral because this is the
2 survey that covers all children.
3 I believe they asked the same
4 question in the other survey that we tabled
5 but this is of all children. This may be a
6 healthy kid and mom comes in and wants a
7 referral to derm for a mole that a general
8 pediatrician or a wart or something that the
9 primary care provider may not only be
10 perfectly capable of but have additional
11 expertise.
12 So the mother says, why are you
13 here? I'm here because I want the referral.
14 You say, well, you don't need a referral
15 because I take care of this all the time and
16 do as good a job as a dermatologist. That's
17 where you run into the problem with this one.
18 CO-CHAIR HOMER: Okay. So let's --
19 MR. STUMBO: Can I interject here?
20 CO-CHAIR HOMER: Oh, you certainly
21 may.
22 MR. STUMBO: Okay. Thank you.

1 The question does specifically say need.
2 CO-CHAIR HOMER: Yes.
3 MR. STUMBO: I think if we're
4 imputing I want from parents which I think is
5 inappropriate.
6 MEMBER LIEBERTHAL: But you're
7 asking the question of parents so they don't
8 discriminate. If they say I want they mean I
9 need. Since you're asking parents, you're
10 using the parent's decision as to whether they
11 need the referral, not whether they truly need
12 the referral.
13 CO-CHAIR HOMER: In the index of
14 family centered care and you're talking about
15 -- I mean, that is the value from which NQF
16 operates and six aims of the Institute of
17 Medicine does put family centered care as the
18 prime value.
19 MEMBER JENKINS: We have to go
20 back to Ellen's question about process versus
21 outcome. I do think that issue about the
22 respondent's bias in the way they might answer

1 this question is an issue. We could ask
2 perhaps both questions to the measurement
3 developer, to that extent do you believe this
4 is an outcome measure? Then also, do you have
5 any data that would look to the validity of
6 presumption of difficulty obtaining a referral
7 when the question is asked in that very
8 general way?
9 MR. STUMBO: Someone in our group
10 has written a paper actually looking at the
11 need and the follow up of referrals from the
12 physician's point of view and from the parent
13 point of view and they don't often jive but
14 there are, indeed, cases in which the doctor
15 indicated a need for parent follow up and the
16 reverse is also true related to a worsened
17 outcome. Within the survey itself, again,
18 this is population based health care.
19 We are able to say that those who
20 were not able to get the referrals they
21 needed, you know, did significantly -- of the
22 child or the rate of the child -- I guess I

1 would say, and I'm not licensed to talk on the
2 phone, but I would say it's an intermediate
3 outcome which is a lack of ability to get a
4 needed referral clearly has fall outcome.
5 CO-CHAIR HOMER: So let's go back.
6 I'm just going to force us back through the
7 process a little bit. Did we vote on the
8 importance criteria? We haven't so I would
9 like to have us vote on whether this meets the
10 importance criteria which is threshold for
11 going forward. Does it completely meet the
12 importance criteria? Just yes or no. Does
13 this meet importance criteria?
14 DR. WINKLER: Yes. Marlene?
15 MEMBER MILLER: Yes.
16 DR. WINKLER: Okay. That's 13.
17 CO-CHAIR HOMER: Okay. No? Two.
18 Okay. All right. So then we need to -- I'm
19 sorry?
20 MS. McELVEEN: I was going to say
21 I still think we need to have a scope vote
22 because there has been some discussion whether

1 this is a process or outcome measure which
2 also would --
3 CO-CHAIR HOMER: I guess -- well,
4 how do we want to -- several of us have felt
5 this is basically an intermediate outcome or
6 a system outcome measure. It's not a health
7 status measure but it is an outcome of having
8 an effect in the delivery system. Therefore,
9 we would consider it under the current
10 deliberations rather than putting it off until
11 July. That would be my suggestion. Should we
12 put that to a vote?
13 MEMBER PARTRIDGE: Charlie, I want
14 to be sure I'm voting on the right thing here.
15 By saying you had no problem obtaining a
16 referral, I assume what you're talking about
17 is even if the pediatrician said, yes, here's
18 a referral to so and so, you couldn't get in.
19 CO-CHAIR HOMER: If you couldn't
20 get in, exactly. You couldn't get approval
21 from your insurance company.
22 MEMBER PARTRIDGE: It's

1 essentially if the child needs the services
2 it's not possible to get them or they don't
3 get them.
4 CO-CHAIR HOMER: Well, again, it's
5 the parent's assessment of how big a problem
6 was it. They said it's either a big problem,
7 a little problem, or no problem. If it's
8 anything other than no problem, it's a problem
9 and it gets scored as a problem.
10 Tom.
11 MEMBER McINERNY: Actually, this
12 time I found the question K5Q10. Great.
13 "During the past 12 months did your child need
14 a referral to see any doctors or receive any
15 services?" I would think that would be the
16 denominator and then the numerator is K5Q11,
17 was getting referrals a big problem, a small
18 problem, or not a problem?
19 There's a bunch of answers; big
20 problem, small problem, not a problem, don't
21 know, refuse. So that could be the numerator.
22 Now, the question is do we lump big and small

1 problems and say, yes, that's a problem, or do
2 we just say big problems?
3 MEMBER JENKINS: Numerators have
4 no problems.
5 MEMBER McINERNY: No problems.
6 CO-CHAIR HOMER: Right, it's no
7 problem. That's exactly right. Again, I
8 think the question still is are we going to
9 consider this as an outcome measure, enough of
10 an outcome measure that we want to continue
11 with the review at this time. Let me call a
12 vote on that. All those in favor of including
13 it within the outcome measure buckets and
14 continuing the discussion.
15 DR. WINKLER: Marlene?
16 MEMBER MILLER: We are voting to
17 call it an outcome measure, yes or no?
18 DR. WINKLER: Correct.
19 MEMBER MILLER: I would say no.
20 DR. WINKLER: Okay. So I got
21 nine.
22 CO-CHAIR HOMER: So all those

1 opposed or who said no, it's a process
2 measure.
3 DR. WINKLER: Marlene will be five
4 so it's 10 to five.
5 CO-CHAIR HOMER: Okay. So let's
6 continue with the conversation then. Thank
7 you.
8 MEMBER McINERNY: Do we have a
9 representative of the steward on the line?
10 CO-CHAIR HOMER: Yes.
11 MEMBER McINERNY: I just have a
12 question about why this measurement was
13 structured the way it is and what you think
14 the potential implications are of putting what
15 would be not traditionally the enumerator as
16 the enumerator being no problem and that all
17 needing referral as the denominator.
18 I mean, obviously those who have
19 no problems identifies those who had problems
20 but is there an advantage of looking at it in
21 this way or is there some data availability
22 issue here?

1 MR. STUMBO: No. I appreciate
2 that question. I was actually going to say
3 something about that. It's funny to think it
4 works this way and I'm now trying to recollect
5 why we defined the measure this way. When we
6 used this, or when others had used this,
7 because this is a measure that does give you
8 quite a bit of literature, we almost always
9 bring that into negative.
10 We do usually talk about the kid's
11 had a problem. The problem there, as someone
12 on the panel was just asking, there are
13 actually three categories; you had no problem
14 or you had a big or a small problem. We do
15 tend to combine the big and small together.
16 Basically what we end up with is
17 yes, you had a problem or, no, you didn't have
18 a problem. Why the question was originally
19 not asked that way I don't know. I wasn't
20 around for the origination on that. We do
21 tend to break up the negatives.
22 I'm sorry that it appears to be

1 there were -- we are definitely more
2 interested in the 20 percent who say they have
3 problems than the ones who don't. Everyone is
4 reading the denominator properly which is only
5 if the parent indicated a referral was needed.
6 MEMBER PERSAUD: In the numerator
7 details the language to me looks different
8 than the numerator statement so the numerator
9 statement is children who need referrals and
10 have no problems obtaining them. Then the
11 numerator detail is the numerator describes a
12 number of children who needed a referral to
13 see whatever and had problems obtaining those
14 referrals.
15 CO-CHAIR HOMER: I think there is
16 a mistake in the --
17 MEMBER PERSAUD: Which one of
18 those things is it and the language should be
19 the same.
20 MR. STUMBO: Sorry about that.
21 MEMBER PERSAUD: So it's had no
22 problems obtaining them or had? If it's had,

1 then the first statement has to be changed.
2 MEMBER JENKINS: -- is higher
3 scored so I think the way is works is no
4 problems.
5 MEMBER PERSAUD: Is no problems so
6 the numerator detail should say had no
7 problems obtaining those referrals.
8 MEMBER CLARKE: That's not a big
9 deal. It's like looking at survival versus
10 mortality.
11 MEMBER RAO: Just one question for
12 the measure developer. In developing this
13 questionnaire what are examples of small and
14 big problems in getting a referral?
15 MR. STUMBO: That's a great
16 question. Again, unfortunately I wasn't
17 around for the development of the actual
18 measure. It doesn't appear to have any --
19 there is no sort help screen, you know, if the
20 parent asks if it means big or small. It's
21 parent perception and I, unfortunately, don't
22 know what that is based on.

1 MEMBER JENKINS: Can I ask a
2 follow-up question about the intent? Was this
3 about insurance referrals or did it mean
4 couldn't get an appointment, couldn't get to
5 the appoint? Was it everything about
6 accomplishing the referral?
7 When you chose the word referral
8 did you mean that literal piece of paper that
9 is the insurance referral? To me in the
10 validity part of this question I didn't think
11 that was completely clear. And then, of
12 course, my follow up question did parents
13 really understand it. Before I get that far
14 what was the intent?
15 MR. STUMBO: I do believe the
16 intent, as someone said earlier, was
17 originally developed for children who need
18 help so that is sort of where it originally
19 comes from. They are using this survey as
20 part of sort of the composite medical whole
21 measure to sort of assist in the performance
22 measure in this regard.

1 Originally what I think it is
2 trying to effect is for kids who have chronic
3 issues with multiple providers and navigating
4 the system which requires often multiple
5 referrals. To what extent at a population
6 level can we measure that. I'm not sure if I
7 answered your question.
8 MEMBER PARTRIDGE: By navigating
9 the system so you mean being able to get an
10 appointment or having somebody help you get an
11 appointment? We have system navigators and we
12 have just plain access problems. I can tell
13 you there are no child psychiatrists in
14 southern Texas or something like that. Which
15 are we talking about?
16 MR. STUMBO: The intent was
17 access.
18 MEMBER LIEBERTHAL: Taking the
19 wording literally it's whatever the parent
20 perceives with the outcome seeing the
21 specialist who they were referred to. What
22 they went through and what the system went

1 through to get them there is immaterial to the
2 parent.
3 If you take this literally, it's
4 what they perceive as the problem. If they
5 want the referral and the PCP says, oh, no,
6 you don't need a referral. That presents a
7 problem. If the system makes it difficult for
8 the PCP to fill out the paper or the insurance
9 company refuses it or there is no access or
10 there are no providers, those are all problems
11 and it's what the parent perceives. Am I
12 reading that correctly?
13 MR. STUMBO: I would agree with
14 that. You would not necessarily be able with
15 these two items to discern the difference
16 between those two.
17 CO-CHAIR HOMER: I think the
18 analogy here is the measure we just had on
19 school days. In other words, this is kind of
20 a global outcome. There could be a variety.
21 I think the lineage of this
22 question is old enough that it probably was

1 during the heyday of gate keeping when the
2 issue may have been issues around is your
3 doctor going to actually write the referral.
4 Now it could be more about shortage of
5 pediatric subspecialists or access to mental
6 health or Medicaid restrictions and benefit
7 levels and things like that, payment levels.
8 MEMBER LIEBERTHAL: Or the child
9 may be -- everything may go smoothly and they
10 may get to the specialist and the specialist
11 is an adult specialist who knows squat about
12 children.
13 CO-CHAIR HOMER: This really is
14 just kind of a yellow flag that says there's
15 a problem and one would need more detailed
16 measurement to find out what it is.
17 DR. WINKLER: Charlie, based on
18 this question and the previous discussion, it
19 sounds like one of our gaps we might want to
20 explore in some detail is while these present
21 global issues, there is a desire for having
22 measures that are a little bit more targeted

1 to answer the questions why that could be
2 looked at the provider level or plan level or
3 system level or something that would be a
4 little more specific to understanding what all
5 the inputs are that this global measure
6 reflects.
7 CO-CHAIR HOMER: I think that's
8 great.
9 DR. WINKLER: Okay. That's a gap.
10 CO-CHAIR HOMER: Okay. So are we
11 at a place where we can vote on the scientific
12 acceptability that specifications,
13 reliability, validity, exclusions, risk
14 adjustment, etc., meaningful differences,
15 comparability, and disparities?
16 PARTICIPANT: Sure.
17 CO-CHAIR HOMER: Sure. I think
18 we're wearing them down. So I'll say to what
19 extent does this completely meet the criteria
20 for scientific acceptability? I see none. To
21 what extent does this partially meet?
22 DR. WINKLER: Marlene.

1 MEMBER MILLER: Yes, I'll say
2 partially.
3 DR. WINKLER: Okay.
4 CO-CHAIR HOMER: And then
5 minimally. We have two.
6 DR. WINKLER: Marlene, I didn't
7 mean to railroad you.
8 CO-CHAIR HOMER: Okay. So do we
9 have everybody then?
10 DR. WINKLER: Yes.
11 CO-CHAIR HOMER: Okay. Good. Why
12 don't we move then onto usability. Is this
13 understandable? Is it harmonized? Are there
14 any other measures around referral management
15 in NQF at all? None? I'm shocked.
16 DR. WINKLER: Except which might
17 be embedded in something like CAHPS or some of
18 the other survey pools.
19 CO-CHAIR HOMER: Does CAHPS -- do
20 we know if CAHPS has anything on --
21 DR. WINKLER: It's not just CAHPS
22 actually around children because there are

1 several other survey instruments and I can't
2 remember the questions on them now.
3 CO-CHAIR HOMER: Is this in the
4 group CAHPS?
5 DR. WINKLER: Well, there is the
6 clinician group CAHPS. Remember we have also
7 done several others that are focused around
8 adolescents, YAHCS, and I forget the other
9 one.
10 CO-CHAIR HOMER: I don't think
11 it's in YAHCS or PHDS but I do think it might
12 be in CAHPS.
13 Kathy?
14 MEMBER JENKINS: It would
15 certainly be the --
16 CO-CHAIR HOMER: Yes, supplement.
17 DR. WINKLER: The pediatric module
18 with the chronic? Yes, and we've endorsed
19 that one, too.
20 MEMBER JENKINS: I was going to
21 ask the measure developer about usability.
22 MR. STUMBO: I actually don't

1 know. I'm sorry. I don't recall.
2 CO-CHAIR HOMER: You're living
3 with the illness survey basically. I think
4 maybe that's a note to both the developer and
5 also to --
6 MEMBER JENKINS: Charlie, I will
7 say that this measure, and then the next one
8 we're going to discuss, is around effective
9 care coordination coming out of this group.
10 I think both of these in my mind are speaking
11 towards the new initiatives around development
12 of medical home. To that extent they are very
13 important nationally.
14 CO-CHAIR HOMER: I am struck on
15 the understandability. On one hand it sort of
16 makes sense that you have problems or not but
17 just the debt of conversation around the room
18 suggested that this group, at least, maybe
19 because we have such a glandular knowledge of
20 the health system had a hard time really
21 understanding what having a problem with the
22 referral meant.

1 So if I were reporting to the
2 public that whether they would share that or
3 whether they would get it, I do have a little
4 concern given how much trouble we had as a
5 group getting out head around what this
6 exactly meant. Okay.
7 Why don't we call for a vote. How
8 many feel this completely meets the usability
9 criteria? Zero.
10 Marlene?
11 MEMBER MILLER: No.
12 CO-CHAIR HOMER: No. Okay. How
13 many this partially meets the usability
14 criteria?
15 DR. WINKLER: Ten.
16 CO-CHAIR HOMER: How many feel it
17 minimally meets the usability criteria?
18 DR. WINKLER: Four. Marlene?
19 MEMBER MILLER: I'm a no.
20 CO-CHAIR HOMER: Okay. Did that
21 get everyone?
22 DR. WINKLER: That's it.

1 CO-CHAIR HOMER: All right. The
2 last one is the feasibility. I guess this
3 probably is going to echo the last one which
4 comes from the survey which happens only every
5 four years. How many feel this is completely
6 feasible? How many feel this is partially
7 feasible?
8 DR. WINKLER: Nine.
9 CO-CHAIR HOMER: And how many feel
10 this is minimally?
11 MEMBER MILLER: I'll vote partial.
12 DR. WINKLER: Okay. Thanks.
13 CO-CHAIR HOMER: Now the global
14 recommendation. Do we recommend this measure
15 to go forward for approval or not? All those
16 in favor -- oh, please.
17 MEMBER CLARKE: I think we
18 absolutely need to stipulate that there is no
19 way it can go forward without resolution of
20 which way are they going to look at it and
21 have it consistent throughout the application.
22 CO-CHAIR HOMER: And clean up the

1 specification.

2 MEMBER CLARKE: It has to be

3 changed no matter what the outcome of this

4 vote is.

5 DR. WINKLER: Right. Yes.

6 CO-CHAIR HOMER: Very good. So

7 assuming, again, which I think is pretty

8 technical, pretty straightforward, that they

9 are just not consistent in the definitions

10 throughout.

11 So all those in favor of approving

12 this or recommending it move forward for

13 endorsement to be precise. Okay.

14 Marlene, did you vote one way or

15 the other?

16 CO-CHAIR HOMER: All those

17 opposed?

18 DR. WINKLER: Marlene?

19 MEMBER MILLER: That was a no.

20 CO-CHAIR HOMER: That's a tough

21 one.

22 DR. WINKLER: Nine to six. It's

1 still yes.

2 CO-CHAIR HOMER: It's still yes.

3 All right. Any strong arguments for

4 reconsideration? I guess not. We can reflect

5 on it overnight and if people have second

6 thoughts, we can discuss it tomorrow.

7 MS. McELVEEN: So we can take a

8 short break if you'd like for about 10 minutes

9 and reconvene and wrap up three more measures

10 for the rest of the day. Is that okay with

11 everyone?

12 CO-CHAIR HOMER: I think we're

13 doing great. Terrific. Thank you.

14 (Whereupon, the above-entitled

15 matter went off the record at 3:08 p.m. and

16 resumed at 3:23 p.m.)

17 CO-CHAIR HOMER: Why don't we get

18 started. If we could reconvene. I just want

19 to get started.

20 MEMBER McINERNY: Some of you may

21 realize, may or may not realize, but the

22 American Family of Pediatric Legislative

1 Office is two floors below. I popped down and
2 Bob Hall from there said he wanted to come up.
3 Bob was single handedly the person who got
4 health care reform passed.
5 CO-CHAIR HOMER: I would say it
6 was Marina and Bob together.
7 MEMBER McINERNY: Marina and Bob.
8 CO-CHAIR WEISS: I don't think so.
9 I'll give him credit.
10 MEMBER McINERNY: And, of course,
11 the AAP Legislative Office will be watching
12 closely what happens and making sure that some
13 of the very important things for children that
14 had been promised will actually take place.
15 He's very interested in this process and was
16 happy to hear that it looks like we are going
17 to be looking to CHIPRA measures as well. He
18 just wanted to say hello to everybody.
19 CO-CHAIR HOMER: Thanks for coming
20 up. It's a public meeting. You can make
21 public comments.
22 MS. McELVEEN: Alright. Moving

1 along with the CAHMI survey measures. We are
2 onto the next one. We are on measure No. 38.
3 The title of this measure is Children who
4 receive effective care coordination of health
5 care services when needed.
6 This is a composite measure used
7 to assess the need and receipt of care
8 coordination services for children who
9 required care from at least two types of
10 health care services which may require
11 communication between the health care
12 providers or with others involved in the
13 child's care.
14 We will get started with
15 importance.
16 MEMBER JENKINS: I don't know if
17 you want to say anything, Allan.
18 MEMBER LIEBERTHAL: Kathy, why
19 don't you start.
20 MEMBER JENKINS: In terms of
21 importance, I think similar to the last
22 measure that we looked at this is coming from

1 the National Survey of Children's Health and
2 is clearly square in the national conversation
3 about medical home and coordination of care.
4 What the measure is doing, I
5 think, as we've just heard, is attempting to
6 use a composite of answers from the National
7 Survey of Children's Health to assess
8 effective care coordination.
9 I don't know if people can
10 understand the importance without knowing just
11 a little bit more about the enumerator and the
12 denominator so I think I'll just say something
13 about that and then I have a question for the
14 measurement developer.
15 This one is a little bit more
16 complicated than the others in that the
17 enumerator -- let me start with the
18 denominator which is a little simpler.
19 The denominator are all
20 respondents did a survey of children zero to
21 17 years who needed care coordination and
22 needed care coordination is defined as needing

1 two or more of the following services; a
2 personal doctor or nurse, a mental health
3 professional, a specialist, or the child's
4 doctor felt that the child needed to see a
5 specialist. All the children who meet those
6 criteria are the denominator.
7 The numerator is a composite and
8 the and/or's are a little confusing to me so
9 I think I might ask the measurement developer
10 to clarify them. Parent report. Someone
11 helping to arrange or coordinate child care
12 among the different doctors and services.
13 And then, and I think this is an
14 "and" statement, either the parent reports
15 they have not felt they could have used extra
16 help arranging or coordinating child's care
17 among the different health care providers or
18 services, or the parent reports that they have
19 felt they could have used help and they got as
20 much help as they wanted with arranging or
21 coordinating the child's care.
22 Then I think it's an "and"

1 statement, the parent reports satisfaction
2 with communication among doctors or other
3 providers. It's a little bit confusing and I
4 think what their intent is to ask for when the
5 parent thought there was a need and then that
6 they thought the need was fulfilled.
7 It was a little confusing to me in
8 terms of parent report someone helping to
9 arrange without the criteria about whether or
10 not the family was satisfied. It's a hard
11 sentence to say so I'm not sure if everyone
12 followed that. If we could ask the
13 measurement developer to help clarify the and
14 and the or's in the numerator statement, I
15 think that would be helpful.
16 MR. STUMBO: Sure. I would be
17 happy to do that. Let me first say I think it
18 would be better to think of me as the steward
19 of the steward rather than the measure
20 developer.
21 MEMBER JENKINS: I'm sorry. I
22 misspoke.

1 MR. STUMBO: All these items were
2 developed by the expert panel for the Paternal
3 Child Health Bureau to do both of the national
4 surveys. There were 15 experts across field
5 who came up with these items. That being
6 said, I will do my best to explain and I have
7 actually worked quite a bit with the data.
8 Actually there might be a slightly simpler
9 way. I could discard the denominator and I
10 think it's best to take the denominator at the
11 moment as all children under 17 who use two or
12 more of those technical services that you were
13 describing. There was one that got left off
14 in our office but it's online.
15 The mission is dental care as
16 well. Presumably any child who has used two
17 or more services, has a primary care
18 physician, special care, and mental health
19 professional care are potentially are eligible
20 for some sort of care coordination services.
21 MEMBER JENKINS: So the survey
22 distinguishes between used the services versus

1 needed the services. Is that correct?
2 MR. STUMBO: That's correct. The
3 actual count is the use of those services.
4 For instance, if the child went to their
5 primary care physician during the past 12
6 months but did not see a mental health
7 professional specialist, or even a dentist
8 they would not be the denominator. If someone
9 went to their primary care physician and
10 dentist they could actually be the
11 denominator. They are the denominator I
12 should say.
13 If I can just go ahead, the
14 numerator I think I can maybe make it a little
15 clearer. I'm hoping I can. Really there are
16 two ways of getting into the numerator. I
17 very much understand the confusion.
18 This is something that we worked
19 on quite a bit with the National Health
20 Statistics, Paternal Child Health Bureau and
21 numerous Title 5 groups across the country who
22 really understand the care coordination

1 component because it's not captured elsewhere
2 and we believe this is at least a good turning
3 point although it's probably not the perfect
4 measure.
5 To get into the numerator you
6 could either have fed directly to a series of
7 questions that someone did indeed help arrange
8 care for you based on the fact that you had
9 two or more services. Following on that you
10 either said you got all the help you needed or
11 you didn't.
12 If you said you didn't, then you
13 actually did not receive enough care
14 coordination which you would not be the
15 numerator of the care coordination. You can
16 ask me questions if that's not clear.
17 The second way of getting into the
18 numerator because the technical expert panel
19 determined that term in and of itself often
20 does not make sense to parents. Anyone who
21 used two or more services and reported that
22 they were highly satisfied with the

1 communication between their doctors also could
2 be refused care coordination.
3 It's possible to say, "No, I did
4 not get any help." The thinking from the
5 technical expert panel is that often parents
6 (a) don't know what that means and (b) don't
7 seem to know that they need help or that they
8 could get help. If they had multiple service
9 use and reported that they were highly
10 satisfied with the communication among
11 providers, that also qualified them for care
12 coordination.
13 MEMBER JENKINS: There is a series
14 of "or" statements. Any of the above makes
15 you eligible for the numerator?
16 MR. STUMBO: That could be
17 correct. Right. You could have gotten care
18 coordination and --
19 MEMBER JENKINS: I thought they
20 were "and" statements.
21 MR. STUMBO: Okay. I'm going to
22 look at this while you guys discuss the other

1 thing.

2 MEMBER LIEBERTHAL: I didn't get

3 into the wording as carefully but overall I

4 actually liked this measure for all of the

5 rating factors because it really comes down to

6 whether the parent was satisfied or not and

7 that is really the outcome you're looking for,

8 parent satisfaction. With that as the

9 outcome, I thought it was a good measure.

10 MEMBER McINERNY: Would it be

11 helpful -- again, I found these exact

12 questions. Would it be helpful to read them,

13 Charlie?

14 CO-CHAIR HOMER: Yes, fine.

15 MEMBER McINERNY: "During the past

16 12 months have you felt that you could have

17 used extra help arranging or coordinating your

18 child's care among the different health care

19 provider or services? Yes or no."

20 "During the past 12 months how

21 often did you get as much help as you wanted

22 with arranging or coordinating the care?

1 Never, sometimes, usually."
2 Then, "Overall were you very
3 satisfied, somewhat satisfied, somewhat
4 dissatisfied, or very dissatisfied with the
5 communication among the child's doctor and
6 other health care providers? Very satisfied,
7 somewhat satisfied, somewhat dissatisfied,
8 very dissatisfied." Then there's a thing, "No
9 communication needed or wanted."
10 When you start to try and put all
11 those together it gets a little confusing.
12 MEMBER PERSAUD: So the question
13 is which of those responses, what combination
14 of those constitute the numerator patient
15 perceived got coordinated care. Is that
16 right?
17 MEMBER JENKINS: That's the
18 question I was asking the measurement
19 developer. Then if we have clarity about
20 that, I guess we can vote on importance.
21 MR. STUMBO: Let me take the
22 negative numerator first because I think it's

1 a little bit easier to explain. There are
2 ands and or's when you get into the positive
3 numerator. Did not qualify as having
4 effective care you did not get all the help
5 you needed for care coordination, or you were
6 not satisfied with the care of one provider.
7 MEMBER JENKINS: You mean with the
8 patient?
9 MR. STUMBO: Yes. To get into the
10 numerator you basically had to have received
11 all the care coordination you thought you
12 needed and been happy with communication
13 between providers and been happy. The third
14 one kind of relates to the second one which is
15 if communication is needed between provider
16 and school, coordinated care with school.
17 Again, it's a satisfied or not satisfied
18 question.
19 If you felt you got all the care
20 coordination that you needed, and you were
21 happy with the communication among providers
22 and happy with the communication between

1 providers and the school, then you had care
2 coordination but there is "and" between each
3 of those three things.
4 Now, there are lots of legitimate
5 skips out of all these questions. If you did
6 not need care coordination or didn't need
7 communication, you can still get into the
8 numerator. You were just legitimately out of
9 that component of the measure.
10 MEMBER LIEBERTHAL: So for your
11 numerator if the parent reports satisfaction
12 with communication among doctors or other
13 providers, if the parent answers yes that they
14 were satisfied, do any of the other bullet
15 points mean anything?
16 MR. STUMBO: Well, you do have to
17 have all three components and so if you are
18 satisfied with the communication, that you
19 reported you did not get all the care
20 coordination help that you needed, you would
21 not be in the numerator so it is not helpful
22 to qualify just by saying you were happy with

1 the way your doctor and dentist talked to each
2 other.
3 You could have said you didn't
4 need any care coordination help. This may or
5 may not be clear. It's a huge tree diagram
6 that we try to diagram it out for people.
7 You could literally say you didn't get any
8 care coordination help and didn't need any
9 because you either didn't know you needed any
10 and said you were satisfied with the
11 communication between all your providers in
12 which case you would be a numerator.
13 You could not qualify as a
14 numerator if you said you needed help and
15 didn't get it but were satisfied with
16 communication between your providers.
17 MEMBER LIEBERTHAL: It's getting
18 more confusing.
19 CO-CHAIR HOMER: So let's ask the
20 first question. To the extent we understand
21 what this measure is measuring is it
22 important. We know the concept of

1 coordination is very important but I guess the
2 next question is as measured is this something
3 -- is it measuring something that's important?
4 Do we have indication that this is a big
5 problem or that there is meaningful variation
6 across sites? There's a gap in performance?
7 MEMBER JENKINS: The application
8 does show variation with various levels of
9 other responses in the survey like they have
10 for other measures coming out of the survey
11 which is a little different but I do think
12 they are trained to measure a construct that
13 there is no gold standard for.
14 CO-CHAIR HOMER: So let me just
15 again just to sort of push the process forward
16 a little bit, it seems like why don't we vote
17 then on importance. It sounds like it does
18 meet those criteria but that is a threshold
19 question, yes or no.
20 Is this measure sufficiently
21 important that we want to go through and
22 consider whether it's actually scientifically

1 credible and useful and feasible and all that
2 other good stuff. All who believe it is
3 sufficiently important raise your hand. That
4 looks pretty universal.
5 DR. WINKLER: Marlene, are you
6 still there?
7 MEMBER SCHWALENSTOCKER: I think
8 she may have had to get off.
9 DR. WINKLER: Okay.
10 CO-CHAIR HOMER: Marina is out for
11 a minute.
12 DR. WINKLER: We'll vote her
13 proxy.
14 CO-CHAIR HOMER: Okay. All right.
15 Then let's look at the scientific
16 acceptability dimension and see how we are
17 feeling about those elements again.
18 DR. WINKLER: Just one thing to
19 ask the measure developer. You mentioned that
20 you drew out a tree diagram. Is that
21 something you could share with us?
22 MR. STUMBO: Yes, certainly.

1 DR. WINKLER: Super. For anybody
2 who is going to view this measure going
3 forward that would be very, very helpful. We
4 may not have it right now but I think that is
5 something we do need.
6 MEMBER ZIMA: Just one more
7 question. You had mentioned schools but I
8 noticed in the denominator it says health
9 services. Are you thinking services broadly
10 or within just health care?
11 MR. STUMBO: Yes. That's a good
12 question. Right. These are health services
13 broadly. For instance, there was a mental
14 health or emotional behavioral issue which
15 went through IDT at school it required
16 communication between the school and any
17 number of providers. That's what it's
18 referring to.
19 MEMBER ZIMA: Would it go so far
20 as foster care to put a kid on a home
21 placement risk?
22 MR. STUMBO: No, the question is

1 very specific; does your child require
2 communication between any of the providers and
3 the school.
4 CO-CHAIR HOMER: So parental
5 judgment. If the foster parent felt that was
6 important, they could say yes. It's parental
7 judgment about whether they think that there
8 needs to be communication between that health
9 care provider and the school.
10 Tom.
11 MEMBER McINERNY: Yes. Would this
12 include therapists such as physical
13 therapists, occupational therapists, speech
14 therapists also?
15 MR. STUMBO: That's correct.
16 MEMBER McINERNY: Okay.
17 MEMBER LIEBERTHAL: Getting back
18 to that last line, parent reports
19 satisfaction. It would seem to me that if the
20 responses were negative on the previous three,
21 then the parent would not be satisfied with
22 communication.

1 If the answers were positive to
2 all three, the parent would be satisfied.
3 Since we are really dealing with parent
4 satisfaction, I think this would have been
5 much simpler had you only asked the fourth
6 question or the measure was only based on the
7 fourth question and that's whether they were
8 satisfied or not.
9 CO-CHAIR HOMER: Okay. At this
10 point, again, we have a measure before us. I
11 guess we could recommend they revise it.
12 MEMBER LIEBERTHAL: Yes, that's
13 what I'm getting at is that we could recommend
14 that. It depends on how we choose to
15 interpret those four questions.
16 CO-CHAIR HOMER: So you're
17 suggesting that you would prefer something
18 that simply looks at parent reported
19 satisfaction with communication among doctors?
20 MEMBER LIEBERTHAL: I see this as
21 a patient satisfaction issue and whether the
22 doctors and the other providers thought they

1 had communicated. If they hadn't conveyed it
2 to the parent and the parent wasn't satisfied
3 with the communication, then the system failed
4 the parent.
5 CO-CHAIR HOMER: But communication
6 and coordination are not the same.
7 MEMBER RAO: I thought it was the
8 issue of our they satisfied with the
9 coordination itself, not the actual
10 communication.
11 MEMBER JENKINS: It's actually
12 both. There is another statement of the
13 algorithm under 2(a).21.
14 MEMBER RAO: Right. That's what I
15 was looking at.
16 MEMBER JENKINS: After the
17 beginning with the ands and the ors it says,
18 "Parent reports that they got as much help as
19 they wanted with arranging or coordinating
20 care." That's a parent satisfaction report.
21 Then there is also in addition
22 parent report satisfaction with communication

1 with doctors when needed and further
2 satisfaction with communication between
3 doctors and others involved, e.g., schools.
4 Back to Allan's point, if you just
5 combine those last three without the beginning
6 part, you would have a pure composite parent
7 satisfaction report on both care,
8 coordination, and communication among
9 providers and with schools.
10 It will also solve one of my other
11 validity issues which had to do with would the
12 family necessarily know and identify that
13 someone had helped coordinate care or who that
14 was. I think a lot happens behind the scenes
15 sometimes that parents are oblivious to.
16 MEMBER PARTRIDGE: I did
17 understand this to mean that they were
18 measuring two separate dimensions. What I
19 would call the case management kind of aspect,
20 somebody who facilitates getting records
21 forward and helps you make the appointment and
22 identifies the proper specialist, etc., which

1 is one function.

2 And then there's another dimension

3 we're looking at and that is the dimension

4 around my child saw the specialist. Did

5 everybody talk to everybody else and did I

6 think it all worked out well. That's the

7 communication and coordination of care aspect.

8 Those are two distinct things in my mind.

9 I think Allan is suggesting that

10 we drop the first. Am I right? You're saying

11 that you're satisfied with -- it doesn't say

12 did you have trouble getting to the specialist

13 in the first place. We aren't asking about

14 that anymore.

15 MEMBER LIEBERTHAL: I'm suggesting

16 that it be simplified into one, that the

17 numerator have one statement whether it is a

18 composite statement that includes the others

19 but it not be ands and ors.

20 MEMBER PARTRIDGE: Right, but in

21 crafting that new numerator you would lose, I

22 think, the answer to the question about did

1 you need help essentially arranging to get to
2 the specialist and did you get it.
3 CO-CHAIR HOMER: I think that is
4 almost an impure question. Again, I would ask
5 the steward whether you have done analyses to
6 see how closely correlated are these. Are
7 they measuring the same thing or are you
8 actually commishing two different -- that's a
9 technical term -- two different concepts into
10 the same measure?
11 MR. STUMBO: We have looked at
12 that and I'm not going to argue with what
13 anybody is saying. I happen to agree that
14 they are sort of one is satisfaction of
15 communication and another one is a more direct
16 measure of coordination.
17 The original thinking behind the
18 item again by the technical expert panel is
19 that the component about satisfaction of
20 communication was meant to broaden the
21 numerator indicator and denominator because a
22 vast number of parents who need care

1 coordination actually say they don't know
2 where to get it.
3 When we ask directly did someone
4 help coordinate your care, what they have
5 found among the children with special health
6 care need in the community is that people
7 don't know that's available. They don't
8 really know what it is. The communication
9 needs to be added in to try to cast a slightly
10 wider net. I might agree that these are two
11 slightly different things now.
12 CO-CHAIR HOMER: So I think this
13 is influencing at least my judgment on
14 scientific acceptability of the measure. I
15 don't know what other people are thinking.
16 Also as I'm thinking of this if you look
17 through the elements here it seems like it's
18 well specified but if it took us 45 minutes to
19 kind of understand those specifications, I
20 guess sometimes things need to be complicated.
21 Just because it's hard doesn't mean it's wrong
22 but maybe it's either not sufficiently clear

1 or --

2 DR. WINKLER: I think one of the

3 issues is always conveying the information.

4 I think some of the measures we see with

5 complex risk adjustment methodologies can be

6 quite dauntingly complex to grasp all of the

7 details. To the degree that we can explain it

8 in a straightforward fashion as possible for

9 a wide audience will be important.

10 I think if a tree diagram explains

11 the numerator better than a series of

12 statements that you get lost in, let's go with

13 the tree and whatever works to communicate how

14 the measure is constructed most effectively.

15 CO-CHAIR HOMER: There also sounds

16 like there are some meaningful questions about

17 the validity of this measure because it is

18 taking two different constructs, one being

19 this coordination facilitation which we are

20 not sure parents can record on accurately.

21 Then we've got this thing on satisfaction with

22 communication which is easier to understand

1 but not necessarily the same construct.

2 MEMBER ZIMA: One more issue I
3 think we just need to say for the future and
4 that is that one time contact with another
5 sector doesn't necessarily mean it's
6 coordinated.

7 DR. WINKLER: One other question
8 to the developer. You have mentioned with
9 some of the other measures that you have done
10 some publications looking at the results of
11 some of these. Has there been any work or
12 publication around this particular measure for
13 care coordination?

14 MR. STUMBO: I would need to get
15 that to someone after the fact with the tree
16 diagram let's say.

17 DR. WINKLER: Okay.

18 MR. STUMBO: I don't know off the
19 top of my head.

20 DR. WINKLER: That might be
21 helpful, too.

22 MEMBER JENKINS: I guess what I'm

1 hearing is that it's a very important
2 construct. There is certainly part of it
3 here. It feels a little underdeveloped to me.
4 I mean, at the end of it what I would love to
5 see is however it's measured in the survey
6 that it sort is evaluated in terms of its
7 validity with something else that is
8 reflective of care coordination.
9 I'm just not seeing that quite yet
10 here. That doesn't mean that descriptively
11 looking at the measure this way might not be
12 interesting and it might not be valid as
13 written. I'm just not sure that I can see
14 that right now.
15 CO-CHAIR HOMER: So I guess the
16 question is do we have enough information that
17 we should continue with the voting or do we
18 need to look at some more background
19 materials? My inclination is we probably have
20 enough but I don't know. What does the
21 committee think? Do we want to get more
22 materials from CAHMI or do we want to sort of

1 proceed?

2 The importance we voted on. We're

3 really talking about scientific acceptability.

4 That's where we were right now. I think some

5 people are not even certain about the

6 validity. Are they measuring, what are they

7 really measuring, what evidence do they have,

8 does this correlate with other indicators of

9 good coordination if there are any.

10 MEMBER CLARKE: I get the

11 impression that the committee doesn't really

12 understand it that well right now. There's

13 not sufficient detail in that. We need the

14 tree.

15 CO-CHAIR HOMER: So should we

16 table this then and ask for the tree and some

17 other data before --

18 MEMBER JENKINS: Maybe we could go

19 through the process and we could end up with

20 one of those to be avoided recommendations

21 with conditions or something. I'm back to

22 Allan's point that he liked a lot of it.

1 CO-CHAIR HOMER: Why don't we do
2 the voting then on the scientific
3 acceptability. How many feel this completely
4 fulfills the acceptability criteria? I see
5 none. How many feel it partially meets the
6 scientific acceptability criteria?
7 DR. WINKLER: Four. Okay.
8 CO-CHAIR HOMER: And how many feel
9 it minimally meets the criteria?
10 DR. WINKLER: Marlene? She's
11 gone.
12 CO-CHAIR HOMER: Did we get
13 everybody?
14 DR. WINKLER: Marina and Marlene
15 are gone so now there are 13.
16 CO-CHAIR HOMER: Okay. Usability.
17 That is how understandable this is. Is it
18 harmonized with other measures and does it
19 provide added value. We've had a long
20 discussion about understandability and
21 harmonization. Again, there may be some
22 indicators in CAHPS that gets vaguely at this

1 issue of communication so we are going to need
2 to talk about the added value of this compared
3 to the CAHPS measure.
4 MEMBER PARTRIDGE: Right. I was
5 going to ask if we could -- I'm pretty sure
6 that HCAHPS, the health plan, not hospital
7 CAHPS.
8 CO-CHAIR HOMER: The original.
9 MEMBER PARTRIDGE: Health plan
10 CAHPS has some questions of the beneficiary,
11 of the member, about care coordination.
12 MEMBER ZIMA: And I believe the
13 consumer measures got four items or so
14 specifically asking whether the doctor
15 listened to and understood and appreciated
16 their cultural values and things like that.
17 CO-CHAIR HOMER: Yes, but that
18 doesn't necessarily deal with the issue of
19 communication with other providers which this
20 is at and coordination amongst multiple
21 sectors. This is more about --
22 DR. WINKLER: We can pull the

1 survey tonight.
2 MEMBER PARTRIDGE: I've been
3 reading it so much the last two weeks you
4 would think I'd have it engraved in my head
5 but I'm almost certain there are very similar
6 questions in it.
7 CO-CHAIR HOMER: My recollection
8 was they tried and that they really had a hard
9 time with these. That was when I was a
10 developer which was a long time ago.
11 Okay. So votes then on the
12 usability. How many feel this completely
13 meets the usability criteria? I see none.
14 How many feels this partially meets the
15 usability criteria? I see two. How many feel
16 this minimally meets the usability criteria?
17 I see a bunch.
18 Now the feasibility criteria, data
19 by product of care, electronic, exclusions,
20 inaccuracies, and implementation. Again, this
21 is the survey, another survey, two per year.
22 MEMBER JENKINS: I think the only

1 issue here is the fact there are inaccuracies
2 based on interpretability to the respondent.
3 CO-CHAIR HOMER: So how many feel
4 this completely meets the feasibility
5 criteria? How many feel this partially --
6 right? Isn't that the next one? Okay,
7 partially. Minimally? All right. Now a
8 global vote on: do we want to recommend this
9 go forward? Again, there are
10 different ways we can recommend to go forward.
11 We can recommend it go forward as endorsement.
12 We can recommend a conditional endorsement,
13 that is, with criteria for some modification
14 or testing or clarification, a time-limited --
15 DR. WINKLER: This really wouldn't
16 be.
17 CO-CHAIR HOMER: This wouldn't be?
18 DR. WINKLER: No. It's been
19 tested. Time-limited is available for
20 measures that have never been tested.
21 CO-CHAIR HOMER: So this is either
22 endorsed or recommend for revision and

1 clarification, to give us more information and
2 come back.
3 MEMBER JENKINS: We've recommended
4 with conditions before.
5 CO-CHAIR HOMER: Okay.
6 MEMBER LIEBERTHAL: When you say
7 this has been used, has it been used in this
8 form, or the individual questions have been
9 used?
10 CO-CHAIR HOMER: I mean, this
11 aggregate -- again, you can go to the website
12 and find out how your state does compared to
13 another state, so that is the use in that
14 context.
15 MEMBER JENKINS: In the composite?
16 I don't think that's right. I thought it was
17 just in the individual component.
18 CO-CHAIR HOMER: No. You can go
19 on the composite. You can compare right now,
20 for example, children who did or didn't need.
21 You can compare it by state -- again,
22 nationally, it says 58 percent did not need

1 care coordination; 28 percent received all the
2 care coordination they needed; and 12.9
3 percent did not receive care coordination as
4 needed which is the --
5 MEMBER LIEBERTHAL: But those are
6 different.
7 MEMBER JENKINS: Those are
8 questions.
9 MEMBER LIEBERTHAL: Those are the
10 individual questions, not the composite.
11 MEMBER JENKINS: Not the
12 composite. That was my understanding, is that
13 the composite was new.
14 MR. STUMBO: It's there. It is
15 there.
16 CO-CHAIR HOMER: The composite
17 using this --
18 MR. STUMBO: In addition to all
19 the individual items, so you can see sort of
20 how many said yes or no to each of the six
21 items total.
22 CO-CHAIR HOMER: Yes, I mean, the

1 question I just gave says it's from question
2 22, 24, 30, 31, 32, etc. It's a component of
3 the medical home composite. Isn't it?
4 MR. STUMBO: That is correct.
5 CO-CHAIR HOMER: So it is widely
6 reported and actually fairly widely published.
7 Okay.
8 MEMBER LIEBERTHAL: Before we
9 vote, can I ask you a question then?
10 CO-CHAIR HOMER: Sure.
11 MEMBER LIEBERTHAL: If they are
12 using it widely in the format it's in, is
13 there any point in our either recommending
14 with conditions, versus not recommending?
15 CO-CHAIR HOMER: Again, the reason
16 that it would be important for NQF either to
17 recommend or not is the use in Medicaid and by
18 CMS.
19 MEMBER LIEBERTHAL: I'm not saying
20 recommending or not recommending, but having
21 the third alternative -- meaning with
22 conditions. Seeing that they are already

1 using it in its current form, is there any
2 point in our asking for conditions?
3 CO-CHAIR HOMER: Yes, because if
4 we recommend it, if the group is fine, then we
5 can go ahead. If we don't recommend it, then
6 it's not going to be eligible for use in these
7 variety of contexts. If we recommend it with
8 conditions, then they could modify it and it
9 could still be then used in another testing.
10 Is that right?
11 DR. WINKLER: I'll split the
12 difference with you. The fact is, you can
13 make the conditions, but it's a no vote unless
14 they do make the changes. For a measure that
15 is well established and well in use, you know,
16 the likelihood of rapid modifications doesn't
17 seem very great. I would be more than happy
18 if the measure developer would jump in and
19 respond as well.
20 MR. STUMBO: I'm sorry. I missed
21 the last question. I apologize. What was the
22 question?

1 DR. WINKLER: The committee
2 members have had some recommendations on the
3 various components of the measures, and if
4 they were to recommend this measure with --
5 conditioned on adjusting the measure
6 somewhat, how likely would it be that would
7 even be possible from the measure developer's
8 perspective?
9 MR. STUMBO: From the discussion
10 I've understood so far, it would be possible
11 for us to calculate two different -- kind of
12 separate out those two components we were
13 talking about, which is the more direct
14 measure of care coordination versus
15 communication satisfaction among service
16 providers, and that is feasible. It's not
17 currently how we think about it, but it is
18 something we've talked about doing, given the
19 items that are surveyed.
20 MEMBER PARTRIDGE: And am I right,
21 that this is one of the components of the big
22 survey that is administered once every four

1 years?
2 MR. STUMBO: Correct. It's
3 actually every two years from the fact that
4 the exact same measure is included in the
5 national survey for children with special
6 health care needs.
7 MEMBER PARTRIDGE: Right.
8 MR. STUMBO: So every two years
9 these exact same items are being asked, either
10 of all children or children with special
11 health care needs.
12 CO-CHAIR HOMER: So if we were to
13 put conditions, what would the conditions be
14 that we would like to add, before calling for
15 a vote?
16 MEMBER PARTRIDGE: I would be
17 interested in seeing it coming back as two
18 separate measures.
19 MEMBER RAO: One for satisfaction
20 and one for coordination.
21 CO-CHAIR HOMER: So I see that
22 then that we're tabling it, or we are not

1 approving it as is, and inviting them to come
2 back rather than approving with conditions.
3 MEMBER JENKINS: I need
4 clarification about what it is, and then my
5 question is not about use but about
6 validation, in terms of what it means. If I
7 understood the algorithm better and it had
8 been validated, then it may be approvable in
9 my mind the way it's written. I just can't
10 get clarity around that. I understand it's
11 being used. It's in the survey and there are
12 answers within the survey, but to me that is
13 very different than being validated for any
14 external standard. That's where I'm not
15 understanding if it's in one concept or two.
16 CO-CHAIR HOMER: So, Reva, what is
17 your sense then of what would be better here?
18 My sense is if we were to just vote it up or
19 down as it is now, probably people -- my guess
20 is we're not going to approve it, but there
21 seems to be interest, and some of that is
22 based on not being able to understand it as it

1 is and wanting to see more analyses.
2 DR. WINKLER: I think that one
3 option is that you could say that you just
4 don't have enough understanding of the measure
5 at this point to vote on it. And perhaps with
6 the additional information that we've
7 discussed with the measure developer -- the
8 tree, any publications, things like that --
9 perhaps that would be the sufficient
10 information you would need, and then you can
11 go ahead and make a judgment. I'm seeing
12 nodding heads.
13 CO-CHAIR HOMER: I think so. I
14 was in a side bar. I'm sorry. I was being
15 bad.
16 DR. WINKLER: I know you were in a
17 side bar.
18 CO-CHAIR HOMER: You solved the
19 problem. This is it.
20 DR. WINKLER: They all decided
21 they prefer not to vote until they have the
22 additional information.

1 CO-CHAIR HOMER: That's good.
2 MEMBER JENKINS: For that last
3 point, please bring the information about the
4 individual components, because we are hearing
5 a call for that information.
6 CO-CHAIR HOMER: Individual
7 components, the coordination and the
8 communication as two separate items. We want
9 separate and together, and we want to see the
10 algorithm as well.
11 DR. WINKLER: Tomorrow?
12 CO-CHAIR HOMER: Well, tomorrow if
13 they have them. The other would be if there
14 is any validation data that cross-matches this
15 with any concurrent kinds of information. If
16 it's been used in programs, for example, where
17 they have online communication between
18 providers -- do you see different kinds of
19 responses in the survey or something like
20 that.
21 DR. WINKLER: Charlie, let's ask
22 the measure developer. Is any of that

1 information something you could email to us
2 now or this evening so, that we can share
3 them?
4 MR. STUMBO: I can try.
5 DR. WINKLER: Okay. We'll be
6 looking for it and we'll share it with the
7 committee as soon as we see it. Thank you.
8 MS. McELVEEN: All right. Moving
9 on to the next measure. It's Measure 39. The
10 title is "Children who live in communities
11 perceived as safe." This measure ascertains:
12 Do parents perceive safety as the child's
13 community or neighborhood? Comments and then
14 discussion.
15 MEMBER LIEBERTHAL: This was,
16 again, Group 3. They don't define the word
17 "safe." Depending on who you are, where you
18 live, safety can have a very different
19 meanings. It's important to know if
20 communities are safe but again -- very similar
21 to others -- we are dealing with patient
22 perceptions, and without more understanding of

1 what is meant by safe, I don't know how people
2 would respond to it.
3 MEMBER DOCHERTY: Family A or
4 family B -- you know -- have different
5 definitions of what safe is, in whatever way
6 they define that to be.
7 MEMBER LIEBERTHAL: The problem I
8 have is, again, if we're trying -- this is
9 solely for calculations. It depends on how
10 you analyze it. In Los Angeles parents who
11 live in South Central may consider safety that
12 they can go a month without a drive-by
13 shooting, whereas a family in the suburb think
14 the neighborhood isn't safe unless they can
15 walk unaccompanied down the street at night at
16 2:00 in the morning without fear of being
17 splashed by a car going through a puddle.
18 Very different worlds. In this case, I don't
19 accept the perception of safety as being true
20 safety.
21 MEMBER JENKINS: I also was in
22 group 3,and I struggled exactly over this

1 dynamic and came down, I think, a little bit
2 to the idea that perception of safety is
3 probably an outcome measure all by itself,
4 regardless of safety for sure are defined
5 differently.
6 I then struggled a little bit
7 about scope for the committee and this work.
8 It was fairly far from sort of health
9 outcomes, so I know we did cast a very broad
10 population-based net, and this was sort of
11 pushing my boundaries there.
12 Then we have the whole issue of
13 the survey methodology and all the rest of it,
14 so I was really curious what other people on
15 the committee thought about scope for this
16 question.
17 MEMBER RAO: I just want to point
18 out -- the questions themselves are actually
19 frequency-type questions; how often does your
20 child feel unsafe or safe in their
21 neighborhood. They are not about how do you
22 perceive the neighborhood in general. I think

1 that makes it a little better indicator.
2 MEMBER FISHER: I do see how this
3 relates to health, because if you perceive
4 yourself as not being safe, that's a stressor.
5 And then the other thing is if it's not safe
6 and you are trying to keep your child from
7 danger, like you said, drive-by shootings, and
8 you stay in the house and you sit in front of
9 the TV more and you play video games more and
10 you put on more weight and you don't do things
11 that keep you quite as healthy. So I do see
12 this as, what do you call it, one of the
13 social determinants of health and a very
14 important one.
15 I do understand what they are
16 saying about the perception, so it may be that
17 if you took this and you got people's
18 perception, maybe the comparison would be some
19 national standard that says whether it's safe
20 or not. But, you know, it depends on how you
21 look at it. But it's important.
22 It's the same thing as, you know,

1 if your doctor comes in and asks you on a
2 scale of one to 10 what your pain is, and they
3 are trying to find out, they need to ask you
4 what is the worst pain you felt, because the
5 worst pain you felt may have been being hit by
6 a car, versus someone who fell down the
7 stairs. I understand the problem
8 with that, but if you're just trying to sort
9 of give how it affects people and their
10 perception and maybe the quality improvement,
11 then you don't want to put out the people that
12 are not safe. I don't know.
13 CO-CHAIR HOMER: I want to
14 reinforce, I think, both of your comments. I
15 think it was a great question, Kathy, in terms
16 of business and scope, but I do think you
17 pointed out the exact two reasons that it is.
18 The whole life course work on the impact of
19 stress and now the static load and all the
20 jargon that our colleagues talk about.
21 This definitely relates, and it's
22 not exactly the same the other indices of

1 stress. Safety has its own slightly unique
2 dimension to some of the other areas, so I
3 think from that perspective as well as the
4 physical activity one it makes sense.
5 Again, Allan, to your point -- it
6 isn't precise and it varies, that's true. To
7 my point that's not the same as SES, which is
8 true but it certainly correlates. Again,
9 while we are talking I looked it up. For
10 parents who report their child is never safe -
11 - using the frequency -- if you are less than
12 the poverty level: 6 percent, 5.9 percent.
13 If you are 100 to 200 percent, 3
14 percent. It's not quite monotonic because the
15 200 to 300 percent is 1.7 percent, and 400
16 percent or more is 0.8 percent. So if you are
17 less than 100 percent of poverty, 6 percent
18 say you're never safe, and if you are over 400
19 percent less than 1 percent say never safe.
20 So it's not perfect, so obviously
21 there are some people in wealthy neighborhoods
22 or who are wealthy report that, but the odds

1 ratio is six. The relative risk is six, and
2 that's a pretty powerful effect.
3 MEMBER LIEBERTHAL: When I was
4 looking at this, I wasn't thinking in terms of
5 looking at subsets of the population. I was
6 looking at it as an evaluation of the overall
7 population. So if you are looking at subsets
8 as you just reported, then it makes a lot more
9 sense to me.
10 CO-CHAIR HOMER: I used that more
11 as a psychologist, you know, it's really just
12 a validation. You would predict that feeling
13 unsafe would be correlated with poverty, and
14 it is in a pretty strong way, so it's really
15 just an indicator that it's not -- even though
16 there is individual variability on perception
17 of safety, this at least provides some
18 concurrent or convergent validity.
19 MEMBER LIEBERTHAL: But in
20 response to my issue of improving quality --
21 because now you could say if you are below the
22 poverty level and last year six percent felt

1 safe and next year 15 percent felt safe --
2 then you've had improvement.
3 MEMBER RAO: I just want to get
4 back to the issue of frequency, and I think of
5 safety more broadly. One of the things is
6 bullying, which is a big issue. That wouldn't
7 necessarily be neighborhood-dependent. It's
8 how often your particular child is bullied.
9 CO-CHAIR HOMER: Which is a very
10 good point.
11 MEMBER FISHER: You know, the
12 other thing is that I know that we say safety
13 is a matter of poverty, but I'm beginning to
14 think that's changing. We need to measure it
15 over time.
16 I mean, the thing I was thinking
17 about is the more time you spend inside and
18 the more time you play those video games, the
19 more desensitized you get to reality and guns
20 and what they do, and then we see this in
21 schools that you would not consider poor
22 neighborhoods. To me I think that's changing,

1 especially if you're not safe and you put in
2 drugs.
3 CO-CHAIR WEISS: I just wonder. I
4 would like to put the question, I suppose, to
5 the clinicians in the room, and that is: how
6 do you use the results from this kind of a
7 population-wide measure in your practice in
8 dealing with the individual child, if you
9 know, for example, that the child comes from
10 a particular part of the community or the
11 state or whatever -- where maybe the incidence
12 of responding to this question in more urgent
13 terms is higher? What do you do with that
14 information?
15 CO-CHAIR HOMER: I think there are
16 several things you do. One is, as a health
17 professional, get involved in advocacy around
18 your community. No. 2 -- really going to
19 Goutham's point. You would also explore -- I
20 mean, if somebody would report this to you on
21 a clinical level and they said they were
22 unsafe and you could then explore issues

1 around bullying, for example, and strategies
2 for dealing with peer interactions and how you
3 might approach that. So I think there are a
4 variety of things you could do.
5 CO-CHAIR WEISS: And this would be
6 equally good or better measure than a straight
7 patient history?
8 MEMBER LIEBERTHAL: I don't see
9 this in the clinical office on a patient-by-
10 patient basis. Again, it depends on where
11 your practice is and the neighborhood that
12 your patients come from. It may color your
13 history taking globally, but I don't know that
14 it does on a patient-by-patient basis.
15 CO-CHAIR WEISS: Okay. Just in
16 the interest of disclosure, my sense is this
17 is an important question to ask, to get kind
18 of a complete picture of how children are
19 growing up in America. My sense also is that
20 it has greater application in the juvenile
21 justice arena, or perhaps in housing or areas
22 outside of medical care.

1 CO-CHAIR HOMER: Tom.
2 MEMBER McINERNY: Yes. I think
3 some of the recommendations you would make
4 would be if they don't feel a neighborhood is
5 safe and you say your child needs some
6 exercise and why don't you have your child
7 walk around the block five times, that's not
8 going to be a very good recommendation in a
9 nonsafe neighborhood.
10 You are going to have to figure
11 out something else, and maybe get a treadmill
12 downstairs or something so that they can
13 exercise within the home or wherever they are
14 as a safe place, those kinds of things. This
15 does get to the millennial morbidity and it
16 does get to the Academy of Pediatrics as
17 having the residents understand sort of the
18 pediatric links with the community type of
19 thing, understanding the environment your
20 patient comes from. It's very important for
21 you to understand a whole bunch of things
22 about them, and how you recommend that they

1 provide care.

2 CO-CHAIR HOMER: Sharon.

3 MEMBER DOCHERTY: That just made

4 me think about high-risk behavior, and

5 understanding what potential high-risk

6 behavior they may be involved in, based on the

7 community they live in.

8 MEMBER ZIMA: I was thinking in

9 that line as well and also the higher risk of

10 exposure to things like drugs and guns. Then

11 I think clinically, even though this doesn't

12 relate to the indicator, you are always

13 wondering about violence in the home as well

14 and that would probably come up clinically if

15 this indicator came up positive.

16 MEMBER JENKINS: The other thing

17 on my mind, and I'm struggling with this

18 obviously, that's why I asked all of you, is

19 Nancy's comment about scope and what's

20 changing and thinking about terrorism,

21 thinking about 9/11, thinking about the

22 reaction of the pediatric community, the

1 children and their reactions to 9/11.
2 I guess maybe from that
3 perspective if we're going to incorporate it
4 as a child health indicator at the population
5 level, it's relevant. If so, I would suggest
6 that this is a very good way to ascertain it
7 at least every four years. It's a direct
8 question, it's about perception. It's from a
9 broad-based survey across the country.
10 MS. McELVEEN: I think it might be
11 worth having our vote on importance and then
12 also scope.
13 CO-CHAIR HOMER: All right. So
14 let's vote on the importance. That is either
15 an up or down vote. How many are in favor of
16 -- view this as sufficiently important to pass
17 our threshold for subsequent consideration?
18 DR. WINKLER: All but one.
19 CO-CHAIR HOMER: How many do not
20 feel it is sufficiently important? All right.
21 So let's move on then to the scientific --
22 MS. McELVEEN: Do you want to do

1 scope?

2 CO-CHAIR HOMER: Scope is a

3 separate question?

4 MS. McELVEEN: It can be

5 sometimes.

6 CO-CHAIR HOMER: Well, okay.

7 DR. WINKLER: I think only because

8 members have raised the issue.

9 CO-CHAIR HOMER: Okay. So, again,

10 I think we've had a pretty robust conversation

11 as to whether it's in scope or not as a broad

12 outcome measure. How many believe it is

13 within scope for our consideration? About the

14 same.

15 And how many believe it is not

16 within the scope? One. All right. Good.

17 Okay. So now let's move on to the scientific

18 credibility or acceptability, that's the word,

19 of the measure. Seems like a straightforward

20 question.

21 MEMBER JENKINS: It's well

22 specified. It's a single question off the

1 survey about perception as we discussed.
2 CO-CHAIR HOMER: Let's see, my
3 little thing says it's really one question.
4 It's section K10, question 40. Right?
5 Children whose parents report their
6 neighborhood or community is never safe for
7 children, sometimes safe.
8 DR. WINKLER: It's defined as
9 usually and always safe.
10 MS. BOSSLEY: It's right under
11 your numerator details on 2a.3 as projected.
12 It is split into two. You're right, they've
13 got two questions: how often do you feel the
14 child is safe in the community or neighborhood
15 and would you say never, sometimes. They just
16 get to the ranking of it.
17 CO-CHAIR HOMER: Okay. So it's no
18 and then how bad it is. So do we feel
19 comfortable making votes about the scientific
20 acceptability? How many feel it completely
21 fulfills the criteria for scientific
22 acceptability?

1 DR. WINKLER: Ten.
2 CO-CHAIR HOMER: How many feel it
3 partially meets the criteria? Okay. Is that
4 everybody?
5 DR. WINKLER: Yes, it is.
6 CO-CHAIR HOMER: Okay. Good.
7 Okay. And then moving onto the usability.
8 Any discussion? So on the general population
9 every four years because of special health
10 care needs would presumably get this question.
11 I don't know. Can we ask our steward?
12 MR. STUMBO: It's actually not in
13 the other survey.
14 CO-CHAIR HOMER: Okay. So this is
15 every four years. Harmonization, again, there
16 are lots of other measures of community
17 wellness and exposure to safety and violence.
18 I just did a session on the EDI which is being
19 used across Canada and Australia and Orange
20 County and a bunch of other places like that.
21 I guess none of those have been submitted so
22 we don't have to worry about them.

1 MEMBER FISHER: I think what I see
2 about this is that this has been used before
3 and I think it would be important to keep
4 using it and it may be that we need it more
5 frequently just to see how things are changing
6 over time. The fact is -- and also to get rid
7 of some of our perceptions because I think
8 that about feeling safe it is changing.
9 As Kathy brought up, I have to say
10 that when I thought about someone setting that
11 bomb off in New York, I was thinking, oh my
12 God, this is going to be like when I went to
13 England and I didn't go to Harrod's and I
14 didn't go to some stores at Christmas time
15 because I'm worried about the IRA because
16 that's a reality. To me it's a big
17 difference.
18 The other thing is even in
19 neighborhoods, I had a friend in Detroit that
20 I was talking to on the phone, on my cell
21 phone, as I was going to the ATM at 10:00 at
22 night yelling at me about going to the ATM at

1 10:00 at night.
2 I was trying to tell them that I
3 was not in Detroit and where I lived I could
4 have even jogged to the ATM at 10:00, but I
5 couldn't jog. I just had knee surgery. The
6 person was really screaming at me and I'm
7 thinking, no, no, no, I don't live there. As
8 I travel across the country, I perceive myself
9 as safer in some places than in others. I
10 just think this is a really important thing.
11 I think it affects your life and it's going to
12 affect our health. It's not just poor people
13 that have guns, you know. There are a lot of
14 wealthy people with lots of guns.
15 CO-CHAIR HOMER: All right. Did
16 we already vote on usability then?
17 MEMBER FISHER: No.
18 CO-CHAIR HOMER: So let's vote on
19 usability. Does it completely fulfill the
20 criteria for usability? Does it partially fit
21 the criteria for usability?
22 MS. WAUGH: It's everybody at 14

1 for partially.

2 CO-CHAIR HOMER: All right. So

3 let's then take an overall.

4 DR. WINKLER: You need to vote on

5 feasibility.

6 CO-CHAIR HOMER: Ah, sorry. How

7 could I forget that? We're doing all right.

8 Feasibility. So this is a survey measure.

9 Just like all the other survey measures this

10 is every four years. Presumably there is some

11 level of inaccuracy, as Allan has mentioned.

12 Okay. How many feel this completely fulfills

13 the feasibility criteria?

14 DR. WINKLER: One.

15 CO-CHAIR HOMER: How many feel it

16 partially fulfills it?

17 DR. WINKLER: Everybody else.

18 CO-CHAIR HOMER: Okay. All right.

19 Now we can move to the global recommendation.

20 MEMBER McINERNY: One quick --

21 what's to stop a pediatrician when they are

22 doing their annual health assessment to ask

1 the parent, do you feel your child is safe in
2 your neighborhood?
3 CO-CHAIR HOMER: I believe there
4 is a whole kit that the academy has put out
5 about violence prevention and all that from
6 Bob Sege and company. Does it include this
7 question or not? Do you know?
8 MEMBER McINERNY: I don't know.
9 MEMBER LIEBERTHAL: There is
10 nothing to stop a pediatrician from asking the
11 question about the safe neighborhood just by
12 looking at where they live already should know
13 whether it's a safe neighborhood. Whether
14 they are safe in their home is a different
15 question.
16 MEMBER McINERNY: Or did they feel
17 safe is the question.
18 MEMBER LIEBERTHAL: Or safe in the
19 school.
20 CO-CHAIR HOMER: Let me go back
21 and call for a vote for all those in favor of
22 recommending endorsement of this measure. The

1 short answer is you measure late in the day.
2 How many opposed? One. Good. Okay.
3 So moving on then to our very last
4 measure: children who live in neighborhoods
5 with certain essential amenities.
6 MS. McELVEEN: So it sounds like
7 some of the same discussion.
8 CO-CHAIR HOMER: Similar but not
9 the same.
10 MS. McELVEEN: Some of the same
11 discussion points may come up. This measure
12 creates a count or a composite measure
13 designed to assess whether or not children
14 live in neighborhoods which contain elements
15 that are known to have an impact on health,
16 status, and functioning.
17 CO-CHAIR HOMER: And what are
18 those measures?
19 MEMBER RAO: Sidewalks.
20 MEMBER JENKINS: This says you
21 need to have all and all includes -- sorry.
22 Give me a sec. Sidewalks. Go ahead. If you

1 have them you can read them.

2 MEMBER McINERNY: Sidewalks,

3 walking paths, a park or playground area, a

4 recreation center or community center and a

5 library or a bookmobile.

6 MEMBER JENKINS: To me, I guess, I

7 have my same question in terms of importance

8 as before. They all sounded great. All

9 children should have them. On the other hand,

10 was this a child health outcome measure I

11 wasn't sure and was going to ask the

12 measurement developer and panel about scope

13 and about the link to the kind of rationale

14 for this being a child health outcome measure.

15 CO-CHAIR HOMER: I might comment

16 this one sounds more structure and processy.

17 The other one was a perception of safety which

18 is an experience which can have a pretty clear

19 biologic correlate. Well, this one is

20 basically do various services and programs

21 exist in your community which may be

22 correlated, but in that sense it's more like

1 either a structural measure, you know, what is
2 the nursing ratio in your hospital, or a
3 process. More structure than anything else.
4 MEMBER FISHER: I don't think a
5 sidewalk is an essential amenity. I'll just
6 say, okay, there are some very, very nice
7 neighborhoods that do not have sidewalks.
8 There is one here because I think I was on
9 Wisconsin in Georgetown and I can't even tell
10 you where people took me. I didn't even know
11 this neighborhood existed where I could
12 probably afford a quarter of their driveway.
13 Is it this Fox something?
14 Foxhall, yes. They don't have
15 sidewalks and there are suburbs that don't
16 have sidewalks.
17 CO-CHAIR HOMER: But they are
18 not -- this is on the structural thing so this
19 is part of the issue of creating health,
20 promoting healthy eating and active living and
21 all that sort of stuff.
22 MEMBER JENKINS: The developer

1 leads it in the same way as they did with safe
2 neighborhoods to physical fitness.
3 CO-CHAIR WEISS: Let me also
4 mention as the mother of an architect who does
5 a lot of city planning and so forth, there is
6 a bit of a difference of opinion within that
7 community. There are those who say that
8 greenery is more important than pavement.
9 Whereas it's important to have a safe place
10 for children to play, the tradeoff between
11 whether it should be a paved environment
12 versus grass and such is a real debate.
13 CO-CHAIR HOMER: You campaign
14 against sidewalks?
15 MEMBER LIEBERTHAL: Parks and
16 playgrounds may be among the most dangerous
17 places in the city.
18 DR. WINKLER: I would like to ask
19 the measure developer what the evidence --
20 CO-CHAIR HOMER: I'm sorry. Let's
21 ask the measure developer.
22 DR. WINKLER: Could we ask the

1 measure developer what the evidence is that
2 this measure is based on for both the
3 sidewalks and the playgrounds in terms of the
4 relationship to health outcomes for children?
5 MS. ELDRED-SKEMP: I'm not exactly
6 sure, but the measure is new, it was just in
7 the 2007 report, but I know that the technical
8 expert was involved in this issue. But I'm
9 not sure about this particular measure.
10 MEMBER RAO: These are all
11 measures of what is called a built environment
12 which is associated with rates of obesity and
13 other health-related behaviors. They are
14 legitimate measures. Most of the data comes
15 from epidemiological type studies that
16 correlate these characteristics with better
17 health and it's a pretty strong correlation.
18 There are actually some, a very
19 small number of studies, that show a
20 transition that when you improve the built
21 environment, children's health does improve
22 within the following years so very legitimate

1 question.

2 MEMBER JENKINS: The libraries are

3 included and is that true in the composite

4 format as written with all four?

5 MEMBER RAO: The libraries I don't

6 know about.

7 CO-CHAIR HOMER: I mean, my sense

8 more we're talking about environments to

9 promote physical activity which are related to

10 obesity. A library I think is just another

11 important element of intellectual development.

12 I think we have actually done -- I think from

13 an importance perspective I guess I would say

14 either importance or scope I think we are

15 having a hard time getting our heads around

16 this.

17 Why don't I call for a vote on

18 whether this meets the scope? Should I do

19 scope first or importance? Anyone care? My

20 call? I'm going to say scope first because,

21 again, I think these are more structural

22 measures that are not as clearly linked to

1 outcomes as some of the other ones.
2 How many believe this falls within
3 our scope of work? Raise your hand. I see
4 none. How many feel this does not fall within
5 our scope? There you go. I think that's
6 basically a threshold measure.
7 I think we can take this one off
8 and feel good that we actually not only tabled
9 a measure but actually turned one down that
10 won't be coming back to us until we get
11 constituted as a structured committee as well
12 as a process committee.
13 MS. McELVEEN: Okay. That does
14 conclude our measures that we were assigned to
15 review today which only sets us up for much
16 more fun tomorrow. We have our plate full.
17 I quickly just wanted to mention to the group
18 and I will also remind everyone tomorrow that
19 we will follow up with everyone regarding your
20 availability and willingness to serve on this
21 phase two to look at the CHIPRA measures.
22 Also we will be scheduling a conference call

1 fairly soon.

2 I want to say within the next two

3 weeks hopefully to look at some of these

4 measures that we have tabled. I just wanted

5 to kind of put that in your ear now. We will

6 try our best to get something out as soon as

7 possible in terms of nailing down your

8 availability for that. I just wanted to

9 mention that to the group tonight.

10 Preparing for tomorrow, one other

11 thing. We are reviewing a measure in the

12 morning. It's a measure called healthy term

13 newborn. The measure developer did send me a

14 sort of visual schematic of that measure that

15 may help understand it. I may just forward

16 that to the group tonight just so you can look

17 at it and have it for tomorrow.

18 Are there any questions from

19 anyone about anything?

20 MEMBER PERSAUD: Are we starting

21 earlier tomorrow?

22 MS. McELVEEN: We are. Thank you.

1 Yes. We are starting at 8:30 tomorrow. 8:00
2 breakfast, 8:30 we'll be ready to start up
3 again. Any other questions?
4 CO-CHAIR HOMER: Are there any
5 members of the public?
6 MS. McELVEEN: Are there any
7 comments from the public or audience? You'll
8 have all the comments tomorrow, right?
9 CO-CHAIR HOMER: Okay. Good.
10 MS. McELVEEN: Okay.
11 CO-CHAIR HOMER: Thank you all.
12 MS. McELVEEN: Thank you, guys.
13 Have a good night.
14 (Whereupon, at 4:39 p.m. the
15 meeting was adjourned.)
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