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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Good morning, good morning. Welcome to the Child Health Outcome Steering Committee meeting.

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

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

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

MS. THEBERGE: Theberge.

MS. McELVEEN: Theberge. And Ashley Morsell is also working on a project.
Also, we have Charlie Homer and Marina Weiss who are our lovely co-chairs on this. So I'm just going to allow them to make a few welcome and introduction comments and then we will go ahead and have the Committee introduce themselves and move forward from there. And be sure to use the mic.

CO-CHAIR HOMER: I remind you to press the button. The main reason I did that was to demonstrate the inappropriate and then the appropriate way for speaking.

But, welcome everyone. It's great to see you. We do have a lot of work to do over the next two days. I'm very excited about it. I just want to at least let you -- reemphasize to you my sense of the importance of the work that we are doing here.

This is one of the key committees that is looking at outcomes. It's one of the important committees that is starting to develop a comprehensive set of measures for children's health care. So we are really
ground-setting, I think, in both of those areas. So very excited about it.

We have got a very diverse set of measures we are going to be looking at, things that are from, you know, quite technical, hospital-based measures to quite less technical, broad community-based outcome measures, which is what we asked for when we first met. So we got what we asked for and now we have to make decisions about it.

So it should be fun. With that, Marina?

CO-CHAIR WEISS: Well, I'm delighted to welcome all of you to our two days worth of very intense work on behalf of NQF and moving these measures forward.

I would just say I agree with everything that Charlie has outlined and the only thing I would add is that NQF is a really important player with regard to the consensus process. And so this is a wonderful opportunity for us to launch some pediatric
measures that, hopefully, will set the base
for future work as well.

There is a great deal of interest
in Congress and within the administration and,
hopefully, we will tuck into that agenda and
help set the pace not only for the pediatric
measures, but just for a more robust approach
to quality generally.

So it is terrific to be a part of
this NQF effort and thank you so much, Nicole,
for all the prep work that you and Reva did to
get us ready to spend two days working hard.
So thank you.

MS. McELVEEN: Okay. Just a few
housekeeping items. The restrooms are, as you
exit these doors to your right. There are two
keys located on that back table, if you need
to use the restroom.

Everyone has a thumb drive. That
basically has all of the materials that I have
emailed you over the course of the coming
weeks in one spot. You don't have to use
them, but it may make it easier, rather than kind of fishing through emails and that sort of thing.

The agenda: the copy of the agenda that I sent you yesterday with the final materials was an older copy. We have revised it. So we just made some new copies and handed that out to you also, you know, just so you know.

And also, be sure to use the microphones, as Charlie just alluded to, when you are talking, that's basically so the transcriber can hear the information and also so the participants on the conference call line can also hear as well.

So I would like to just have each Committee Member introduce themselves and also go through disclosures, if there are any, amongst the Members.

MEMBER PERSAUD: Donna Persaud, Dallas, Texas. And I have no disclosures.

MEMBER McINERNY: Tom McInerny
from Rochester, New York. No disclosures.

MEMBER KIBORT: Phil Kibort,
Children's Minnesota. No disclosures.

MEMBER FISHER: Nancy Fisher,

MEMBER CLARKE: David Clarke,
Denver, Colorado. No disclosures.

MEMBER JENKINS: Kathy Jenkins
from the Children's Hospital in Boston. I'm
the Chief Safety and Quality Officer for
Children's Hospital Boston. And we submitted
measures as a steward, the hospital did, and
the program for Patient Safety and Quality,
which I direct.

And I had indirect involvement in
all the measures we sent in and, for two of
them, more direct involvement. So I'm going
to abstain from all conversations related to
any of the measures which we stewarded.

I don't believe I have any other
conflicts with any of the other measures.

MEMBER PARTRIDGE: Lee Partridge,
National Partnership for Women and Families.

No disclosures.

MEMBER ZIMA: Bonnie Zima, UCLA.

No disclosures.

MEMBER DOCHERTY: Sharron Docherty, Duke University Medical Center representing National Association of Pediatric Nurse Practitioners. No disclosures.

MEMBER RAO: Goutham Rao from the University of Pittsburgh. No disclosures.

MEMBER LIEBERTHAL: Allan Lieberthal, Kaiser Permanente, Panorama City, California. No disclosures.

MS. THEBERGE: Hi, everyone. I'm Suzanne Theberge. I'm a Project Manager here at NQF.

MS. BOSSLEY: I'm Heidi Bossley, Senior Director on Performance Measures here at NQF.

MS. McELVEEN: Okay. Do we have anyone who has called in? Committee Members?

MEMBER MILLER: This is Marlene
Miller, Vice Chair at Johns Hopkins Children's Center.

MS. McELVEEN: Great. Thank you, Marlene, for calling in. Anyone else? Okay. So what we are going to do for the first 20 minutes or so is, we wanted just to provide a recap of what we have done to date in the project, essentially, and start to frame our discussion over looking at outcomes and process --

Well, we won't be looking at process measures, but we really want to frame the discussion when we are looking at outcome measures and really talk about what an outcome measure is, what the Committee kind of discussed at the meeting in November to sort of frame the call for measures, which ultimately was the reason why we received some of the measures we did. So I wanted to take a few minutes and go through that.

Our meeting goals, obviously, are to evaluate the standards that we receive
during our call for measures. The Committee will be asked to recommend these measures for endorsement moving forward in our consensus process.

And also, another very important deliverable is to identify gaps for outcome measures in children. And we will set aside time. That type of conversation probably will come up as we go through each individual measure, but we have set aside time at the end of today and also tomorrow to look at gaps and measurement.

So largely, the Outcomes Project is funded by HHS and, as most of you all know, there are three phases to the project. Phases I and II are currently happening now. Phase III includes child health and also mental health.

Our focus is on cross-cutting and condition-specific outcome measures. There is currently limited availability of existing child health outcome measures and so we are
here to expand that horizon a little bit and also expand NQF's portfolio of measures in that particular area.

To date, we have about 68 NQF-endorsed measures focused on child health. Approximately 25 of those are focused solely on outcomes. So there is definitely some room for adding to that number.

This slide illustrates, really, a framework when you think about child health outcomes and some potential domains and ways of bucketing this information. And also, when you look at these domains, this also serves as a frame when you think of gaps as well.

So potential domains include age groups, certainly, you know, adolescents to neonatals. There is many different age groups when it comes to children. Health status is particularly important. Settings of care, looking at hospitals, outpatients. And level of analysis is particularly important when we are looking at these measures.
Most of them are on a population level. As you probably have noticed, a lot of the survey measures are more on a population level, not necessarily on a clinician or provider level of analysis when we are looking at measurement.

Reva, did you want to add any further comments to that?

DR. WINKLER: The only thing I would say to that is, NQF and HHS also are particularly interested in measures at all levels of analysis, not that the individual measure could necessarily meet all of them. There might be a couple of really good ones that could be used at all levels.

But having a mixture of population-level measures as well as provider-level measures as well as clinician-level measures provides NQF with a really robust portfolio that can be used in a variety of ways by different implementors. So all of them are on the table.
CO-CHAIR HOMER: I just want to say my sense is while it is unlikely that any measure can apply to all of them, it seems like it is a desirable attribute. That is, if there were measures that applied to multiple levels, that would be good, because that would simplify the field.

Just maybe an observation, having looked at most of the measures, my sense is that many of the people who submitted measures did not have a crisp idea of what this question meant when they described what level the measure applied to.

So I think that's something we, as Committee Members, are going to have to make our own judgments about and not necessarily rely on what many of the stewards suggested.

MS. McELVEEN: We then moved to data sources for outcomes. Patient or care-provider reported outcome, a clinician-observed outcome, those sorts of things, vital signs, lab results.
This highlights what the call for measures for the Child Health Outcomes Project, what we actually looked for. And we tried to bring this to your attention, because this is really an output from the November meeting where you discussed a lot of this information.

So it was things such as: child and family functioning, school attendance; performance, physical fitness, symptom improvement or relief, growth and development, that includes cognitive, physical, social, emotional growth, parent/patient-reported outcomes, intermediate outcomes, such as blood pressure or BMI percentile, patient or family experience with care, behavioral change.

And we have a second slide here: health services utilization, potentially preventable adverse social outcomes, health care-acquired adverse events, population health indicators.

And one type of measure, in
particular, that NQF normally doesn't get is health care sectors that share responsibilities. And so that's looking at schools, you know, the juvenile system.

I believe that we have a few measures around schools, so those are fairly new to our portfolio when we are looking at, in terms of quality improvement and public reporting and accountability.

Let me just go back a second.

Were there any questions so far? Yes?

MEMBER PARTRIDGE: Nicole, as you ran through that list, that page and the page before, there are some measures in there that I think we all thought we would get, but we didn't. And do you have any sense? I mean, there are three or four that look like no-brainers. Are they not out there?

DR. WINKLER: I think, Lee, that's the question. Do you know of specific measures or specific good ideas? And I think there are a lot of people that would agree
there are a lot of great ideas, but no one has crafted the actual measure yet.

Certainly, we used all of your contacts and everybody you could reach out to and they were not, you know, submitted. So I think there is a certain unknown. There may be measures like that being used at local levels or within facilities for local quality improvement, but perhaps that don't rise to the level that they feel that would be appropriate for submission to NQF.

So I think any number of those would address or apply to various measures.

MEMBER JENKINS: You know, my sense would be that there is two major barriers to this process that, if one is contemplating submitting measures makes it more challenging. And one is the degree of burden of the validation and the current use of the measure. And the second one is the seemingly strict requirement that it be available for high-stakes measurement like
public reporting or P4P.

And depending on people's interpretation of their measure on those two axes, it can be a barrier to submission. So those are very high bars if you take them literally.

CO-CHAIR HOMER: I think there are more measures. There are more outcome measures, certainly, in the pediatric research community that we haven't received. So I think Kathy's hypotheses sound pretty credible to me. But we didn't get them, so we will have to think through afterwards what to do and how to do that.

MS. McELVEEN: Okay.

CO-CHAIR HOMER: I just also wanted to briefly emphasize the importance of the gaps identification. I mean, all of us have participated in projects where, you know, there is always a section that says, "further research is needed", and you come up with a list of 20 things and you know deep in your
soul that nobody ever looks at that list again and it's kind of frustrating.

I think, in this case, we are in a better situation. If you look at, for example, both CHIPRA Legislation and the Health Reform Legislation, it charges NQF, specifically the Health Reform Legislation, for identifying gaps, basically, on an every-three-year basis, and reporting those to the Secretary of HHS, for the Secretary, then, to fund measurement development activities.

So there is a pipeline here that is clearly articulated from the gap identification to, actually, measurement development and then measurement use. So I think it is more than the usual, oh, yes, we didn't get these measures and buried them at the bottom of our report.

DR. WINKLER: Let me just add one thing to that. One of the activities that is going on with the group within NQF that is actually addressing that Directive from the
Secretary on Prioritization is, they actually have gone back through all of our past reports and looked at that section that may not have been previously read and is now being read quite intently to help formulate some of them.

So it may be a little delayed, but all of that effort was not for naught. And so we have been told by HHS from the very beginning that the endorsement of measures is important, but equally important. It is not an afterthought. It's not the appendix. It's not an add-on. It's the gaps analysis.

Because they are in a position to use their resources to develop things appropriately within all of their various agencies within HHS. So it's very much an important outcome of this project.

CO-CHAIR WEISS: And let me just tag on to Reva's point and underscore for you the fact that there is some overlap between this Committee, obviously, and the group that has been working with CMS and AHRQ on the core
measure set and then the second wave of pediatric measures that were called for in CHIPRA.

Now, the reason I raise this is because it is, as Charlie said, not just a matter of coming up with a laundry list of items where further research is needed, but there is development money also associated with CHIPRA. The money is already appropriated; it is available. And HHS is interested in knowing where to deploy and allocate these resources.

So we do have an opportunity here not only to identify gaps, but, maybe, to prioritize and give them some direction on what we think, based on the expertise around this table, are the most promising areas in which to begin work.

DR. WINKLER: Which is sort of a perfect segue to Nicole's next slide.

MS. McELVEEN: We will be looking at CHIPRA measures. Currently, only about, I
believe it is, 6 to 10 of the full set of CHIPRA measures are NQF-endorsed. So we are being asked to look at the remaining set of those measures and also additional process measures for child health and to look at endorsing those measures.

This project, obviously, is closely related to what we are doing now. We are looking to move forward with this project, really simultaneously after we get over the hurdle of endorsing and recommending our first set of measures.

We are looking to just continue the stream and to continue work directly into the CHIPRA Project. Ideally, we would like all of the current Steering Committee Members to continue along with that process. That does mean another in-person meeting and evaluating another set of measures, but, you know, we notice very quickly that the group sitting in front of us is really sort of the cream of the crop and the people that should
be at the table when it comes to child health.

   And we are hoping, if you are
willing and if you, obviously, have the time,
to continue on with that process. And once we
are done with this meeting, we will follow-up
more definitively on dates and to, you know,
get your feedback on that.

   The tentative start date was, we
are looking at July of this year. And when we
say "start", that means that we would start
with a call for measures. And, of course, you
all know that's a 30-day process. So
potentially, an in person meeting would be,
probably, about September or October of this
year and that's just kind of off the top of my
head. So I wanted to mention that to the
group.

   The good thing that most Committee
Members and projects aren't able to do that we
will be is many of the measures that you don't
feel apply to this project and are real
process measures, we then could potentially
review those within the contents of the CHIPRA Project.

And I know that's a challenge for many Committee Members. It's not appropriate for this project, but you're kind of lost in limbo and you don't really know what to do with the measure, because you think it is valuable, but there is potential for many of the measures to be passed on and to move on into this second phase of the project.

And so, when we are looking at next steps, moving from outcomes to CHIPRA, the gaps that you identify within the contents of our two days here will be used, essentially, in our call for measures and also we will be sure to highlight a specific section in the report, as we always do, to highlight those gaps and areas where you think there is room for improvement.

Are there any questions about that?

CO-CHAIR HOMER: Flattery will get
you everywhere. The last Committee I think I
was on with Reva was NQF's longest serving
Steering Committee or whatever it is. So I
have been working it for the duration.

DR. WINKLER: Right. It went on
for three and a half years.

CO-CHAIR HOMER: Yes. I do have a
question though. So I'm a little -- I mean,
the CHIPRA measurement set is a defined
measurement set, at this point. They are the
twenty-some odd, 22, 24 measures. So there
will be a call for additional process and
outcome measures beyond the CHIPRA set?

MS. McELVEEN: Yes.

CO-CHAIR HOMER: To fill in the
gaps for the areas that the Committee
knowledge wasn't there?

DR. WINKLER: My understanding is
even though we have got the first year of core
measures, there is an acknowledgement that it
really is -- there is lots of gaps and it just
doesn't meet everyone's needs.
And there is a desire to evolve it over the subsequent years and add in better measures, remove the ones that are maybe not so good or replace them, revise them, update them whatever, so that there is an evolution of that measure set. And so this will be an important input to the next year's set.

CO-CHAIR WEISS: Well, let me just say that the first wave of measures called for under CHIPRA were selected in part because of the speed with which the legislation contemplated implementation.

And so a great deal of attention was given to what is currently going on in states today. What would be relatively easy to get up and operational at the implementation level? What were the measures that were most comfortable for the state officials who were sitting around the table and so forth?

But there was always an expectation that there would be future phases
to that project and, as Reva said, correction and strengthening of the set of measures that would ultimately be used.

Initially, these are to be voluntary, but over time the direction is to make them mandatory or at least a subset of what is available and mandatory.

MEMBER PARTRIDGE: I would just add a postscript to that, because Marina was on that Committee and I sat in a chair behind her for several days listening to their deliberations and I think you had -- I forget what you called it, the list, putting everybody on the alert that the Committee was looking for, hoping to see measures on something else.

I also wanted to share something, another opportunity for us, and I think this plays in very nicely, that the CHIPRA legislation does direct the Secretary to report to Congress on some areas in which, perhaps, there are some impediments to
effectively getting measures adopted and satisfactorily used.

And CMS is being very open about saying they would love to have comments in whatever form that would help inform that report, which they will be pulling together some time later this year. So I think probably things like our reports and discussions will be useful.

MEMBER MILLER: Charlie?

CO-CHAIR HOMER: Yes, please.

MEMBER MILLER: This is Marlene and I just want to add that I think if we go on and I serve on a Committee that may know the new four measures in the conversation there and it strikes me that looking at the materials we have before us that one of the things that is not explicitly called for, but, you know, I at least would like to see that we entertain it, is that for any measure I applaud the focus on outcomes, that we need to also ask ourselves are there changed packages
that if an institution or a state or a provider or a health plan is not performing well, you can direct them on what to do to actually change that rate.

You know, I think a lot of the measurement work is measurement for measurement's sake with the hopes that just measuring will improve care.

And what we know is that that's not necessarily true. That we need an actual tool kit. When I even look to NQF evaluations, it is sort of implied there, but there is no explicit places that say, list the packages that you know or the efforts that you know have shown to change someone's rate and improve it, so that you give people tools.

CO-CHAIR HOMER: That sounds like a great suggestion. It's really NQF criteria. I mean, again, the definition says the measures have to be used for both accountability and improvement, but you're right, there is not much in there to back that
That sounds like a very, very good suggestion, Marlene. Thank you.

MEMBER MILLER: Okay.

CO-CHAIR HOMER: If I could just—you know, I want to make sure we stay on schedule. I think we have had a good, broad, forward-reaching conversation and I didn't hear anybody in the room say, "Oh, my God, I don't want to be on the follow-up Committee," but you could certainly talk to Nicole afterwards, if that's the case.

This will be a negative check-off process. What is that, benign paternalism? Isn't that what -- anyway, I do want to reframe us, though, back to outcomes for a second -- not for a second, for the rest of the meeting. So while looking forward, we are going to be discussing process measures once we get to July.

Right now, we are focused on measures of outcome. And I just want to
remind the group that measures of outcome are selected because they are what is most meaningful to patients, most understandable to the public. It is what providers hope they are influencing.

They don't measure everything upstream that leads to the outcomes, so those of us in the room who have been involved in -- who either are responsible for hospital or clinical operations, sometimes get nervous when we see an outcome measure, because we think of the 43 other things that could contribute to those outcomes.

And the answer is, kind of, we know that, but we are supposed to come up with measures of outcome that can be used together with other measures of processes and maybe even structures that could lead to those outcomes.

But I say that, in part, because my sense on our phone call with some very complicated measures, which we are about to
segue into, there was some discomfort, really, about looking at outcome measures because it didn't measure the upstream characteristics.

And so I just want to reframe us back on our particular charge, whether we agree with it, you know, whether we have anxiety about it or not, but our particular charge is to identify and potentially endorse, if we think they are of credible measures, measures of child health outcome. Kathy?

MEMBER JENKINS: Thanks for saying that, Charlie, because I think that's helpful to me. I did have a question though, because when I looked at some of the ones that were assigned to me, some of them did feel more like structural and process measures.

And then, I just heard your comment that, where those come up, perhaps we could set those aside for Phase II, if they are not truly outcome measures.

I guess I was under the impression that the NQF staff had screened what we were
getting for eligibility for this project, so that those would have been filtered off. And at least, the approach I took was to kind of assume, since you had given them to me, it was my job to kind of assess them according to the criteria.

But, if that's not the rules, I would like to hear us, you know, kind of set all that for the entire discussion, because I think it may come up in little ways across the board.

DR. WINKLER: And just, essentially, what we have is a moving target, because at the time we did the call for measures, we were intentionally very, very broad. And our interpretation for them were really quite broad.

The advent of the CHIPRA Project and approval for going forward with that is a relatively -- came afterwards. So we are adjusting, as you will.

So if you feel particularly that a
measure is strong in and of itself, but isn't appropriate for outcomes, we do have an avenue to deal with it.

And so we were very loose in terms of screening anything out prior. Again, because two slides worth of how you describe outcomes gave us pretty squishy borders. And so our default was to keep it, rather than kick it.

CO-CHAIR HOMER: I took your approach. I had the same impression you did, Kathy, and I took a different approach, which is, I thought clearly if it was a process measure and we were doing outcomes, I felt it was inappropriate for us to list as an outcome measure and that we would move it into whatever other committee's place it was to deal with. That was my own take.

CO-CHAIR WEISS: Let me just observe, I guess, that the funder for this project is CMS and they, of course, have responsibility or HHS and CMS is intensely
interested in the outcome of these
discussions.

I just raise that because what we
are talking about, when CMS is in the room, is
Medicaid, CHIP and a very large percentage of
children with special health care needs and
also a very large percentage of children with
very good health.

So, to the extent that these
measures are going to make their way into use
with those programs, Congress will be very
interested in how well their investment is
being expended.

Meaning, therefore, that this
discussion we are having about differentiating
between outcomes measures and process measures
is extremely important. And my own sense is
that if the group around the table begins to
frame up the issues in an appropriate way,
that that will essentially be a teaching tool
for the very policymakers who are making
resources available to continue this project.
MS. McELVEEN: One other thing that I just wanted to mention with the CHIPRA. Suzanne will be staffing that portion of the project, so I just wanted to let the Committee know that. And I also noticed that Ellen has joined us.

Did you want to just quickly introduce yourself and, if you have any disclosures?

MEMBER SCHWALENSTOCKER: Yes, my name is Ellen Schwalenstocker. I'm Acting Vice President for Quality Advocacy and Measurement at the National Association of Children's Hospitals and Related Institutions, which is local, which is why I'm late, because I was fighting with the D.C. traffic.

And the only disclosures are, as an employee of NACHRI, we do have data programs that do produce measures. We do not have any in this particular group of measures.

MS. McELVEEN: Thank you. I wanted to just quickly go through our
endorsement criteria. I know you have seen this plenty of times, but it is worth just refreshing. And also, I'll review with you our options for recommending measures for endorsement.

So again, our criteria, we're going to be looking at importance, which is a must-pass criterion and that's where a lot of the discussion will come up is, is this an outcome, is this a process measure? So that will really happen in importance.

If it is not important to measurement report and if it is out of scope for this project, we do not continue with the rest of the evaluation.

We next look at scientific acceptability and the measure properties, which covers a lot of the specifications of the measure, obviously. Usability, a lot of the discussions in terms of the level of analysis will probably come out when we get to usability and also feasibility.
The other thing I wanted to mention is, when you are discussing the measures, it will be sort of a balance and tradeoff in terms of identifying why you like or do not like the measure. So we encourage the Committee Members to really stick to this criterion and identify if, at all possible, within these four criterion what specifically was it that propelled you to recommend it for endorsement or to not recommend it for endorsement.

So again, this goes to those four criterion again.

The evaluation process, you have the measures and you have gone through most of this already. As I mentioned, the measures have to pass importance to continue remaining in our process to be fully evaluated. And what we will do is, we will vote on each of those four main criteria and also receive a vote overall on the measure, whether you recommend it for endorsement or not.
Here are the options. Obviously, recommend for endorsement, do not recommend for and also recommend with conditions. That should be used carefully. Recommending with conditions means that you have specific things that you would like the measure developers to change about the measure.

So if it's a timeframe that is unclear, if they need to clarify the timeframe, if the specifications can be cleaned up a little bit, there are certain measures in which the Committee can provide that recommendation. The conditions have to be clear and we give the measure developer/steward about two weeks to do that.

So your conditions shouldn't be something that would completely change the measure in any way. And they would follow-up with their feedback and responses to those conditions. We then would bring that back to the Committee and you would review them and decide from there whether you want to
recommend it for endorsement.

The other thing that may arise is time-limited endorsement. This only applies to untested measures. And we do have a small handful of untested measures in our complete set.

Recently, NQF has updated their Time Limited Endorsement policy and there are three specific conditions that must be met in order for it to qualify for time-limited endorsement: there cannot be a currently NQF-endorsed measure that addresses the same topic of interest, a critical time line must be met, example, includes a legislative mandate for this particular measure, and the measure cannot be complex, so a composite or any measure requiring risk adjustment would not apply.

Also, there is a time period that the measure steward must agree with to complete the testing and that's 12 months. Previously, it was 24 months. So I just
wanted to make the group aware.

And once we get to those measures where this could be a possibility, certainly, we will bring that to your attention and be able to answer any questions about that.

Lastly, which we may revisit again, it's just our timeline. Again, after this meeting, we are scheduled to go out for public and member comment in June, member voting followed by that in August/September, and CSAC review and Board endorsement in October of this year.

So that's our tentative timeline and I just wanted to go through that quickly with the group. Were there any questions? Questions may arise as we go through the measures. Kathy, did you have a question?

MEMBER JENKINS: I had a question. I heard the part earlier about the next phase of the project. Are you all anticipating there will be another call for outcome measures later or is it just the CHIPRA part?
DR. WINKLER: Actually, what NQF is doing is revisiting with our Board of Directors today actually. Our approach for looking at measures realizing that trying to reconcile what we have and new measures that need to come in is not well-served with sort of the kind of project focus, whether it's an outcome with this or that.

So what we are hoping to move into is sort of a rolling, you know, predictable, every couple of years, there will be a call for all measures around a certain topic area, for instance, child health. And it wouldn't be just outcomes, wouldn't just be process, wouldn't just be hospital. And so we could really look at that aspect of the portfolio in a more comprehensive way.

So again, this is sort of an evolutionary thing. So answering your question, is it something we are able to do right now? We are hopeful that it will be something regular and predictable that will
have a stream to be bringing in new measures, particularly when there is a big push for measure development to occur.

Heidi, did you want to add anything to that?

MS. BOSSLEY: I think we will know when the Board decides today. But the hope is to, again, have committees not look at this one off-piece, here is a few outcome measures that address one condition. Really perhaps get our arms around what does care coordination mean across the board, not only looking at measures that are appropriate for nursing homes when you deal with falls, but also just falls in general across every setting.

So the hope is to be able to really start looking at comprehensive care process, outcome structure, whatever, you know, we can get and again build it into our measure development and endorsement agendas. That's the hope.
MS. McELVEEN: Okay. We are going to segue into briefly reviewing the Committee's discussion and votes on the four AHRQ measures that were discussed via conference call.

And in your packet of materials, you will find a folder in there. Actually, it is a PDF that has the meeting summary from our April 12th conference call and further down, it should be about page 5, we have compiled the results from the Committee's vote on the four main criterion and also the vote on the recommendation for endorsement along with several comments for each measure.

Let me see if I can enlarge this.

CO-CHAIR HOMER: The name of the file is?

MS. McELVEEN: The name of the file is CH Vote/Summary AHRQ Measures. So I have it projected here.

CO-CHAIR HOMER: You're on page 5?

MS. McELVEEN: Yes, five, yes.
Let's see. So we wanted to take some time to really briefly discuss this again. I know, based on the results we got so far, we had about 11 responses.

Essentially, the first measure which was on urinary tract infection admission rate, that measure and also the diabetes short-term complication rate, those two particular measures -- so far the majority was do not recommend.

So I wanted to just kind of get your thoughts about that and maybe re-vote, because we only had an 11 vote, we have about 17 on the Steering Committee, and touch base on those two measures first and then we will go through the other two, which were more likely to pass.

CO-CHAIR HOMER: Right. And had fewer votes.

MS. McELVEEN: Yes. So this first, the urinary tract infection admission rate. The description is just the admission
rate for urinary tract infection in children, ages three months to 17 years-old. Again, this is a population level measure. It looks like most of the responses did agree that this was important to measure and report. But when we looked at scientific acceptability, usability and feasibility, moderate was the rating overall for those. And 8 out of 11 that reviewed this measure requested not to recommend the measure.

Two, recommend with conditions. The comments weren't too specific on what those conditions would be, so we can talk about that, if that's something that we want to do.

Also, I wanted to find out, do we have AHRQ on the phone?

MR. BOTT: Yes. Hi, this is John Bott with AHRQ.

MS. McELVEEN: Okay. Great. I just wanted to make sure. I just wanted to
open it from the discussion with the group.

If there aren't any follow-up comments about
the measure, we can go right into voting on
the criterion, but I wanted to kind of get
your feedback and allow you to discuss any
concerns you had first.

CO-CHAIR HOMER: My recollection
of the major concern was people were not
convinced that there really was a
preventability dimension to the UTI issue.
Although, it is routinely included in the
ambulatory care sensitive conditions, which is
where this comes from, I think my sense of the
discussion was that we were not convinced.
Many of us reviewing this were not convinced
that ambulatory care processes, that there was
a clear link between ambulatory care processes
and this particular outcome.

MEMBER RAO: I think the age range
was a real concern for a lot of people, too.
I think that was a big one.

CO-CHAIR HOMER: So is there any
I need to re-vote or do you want to call a formal --

MS. McELVEEN: I would like to.

CO-CHAIR HOMER: So why don't we call a formal vote then on this? If there are no other questions or discussion of the measure.

MEMBER JENKINS: Charlie, could I ask in terms of your first comment, back to our discussion about processes and outcomes and whether or not all the pathways to the outcome need to be clear in order for an outcome to be important. If people are not -- I just want to be sure I understand the ground rules.

If people aren't -- what you said is that the major discomfort was that people were not confident that ambulatory care processes could prevent this outcome. Is that crucial to the vote or is it really just is this outcome important for child health? If I can get that, because I'm struggling over
the criteria for what this Committee is about.

DR. WINKLER: I think you need to look within the context of quality, because these are -- we are looking to endorse measures that are performance measures, that are quality measures, so the outcome may have a whole variety of inputs, but there should be, at least, some reflection of the quality of those inputs particularly around the provision of the care.

And that's really the context we are looking at. So there are a lot of very important outcomes that may not reflect the quality of care provided. It may reflect the nature of the condition itself.

So there is a difference between outcomes for which it is all about the condition as opposed to outcomes for which we see a lot of variation in care or variation in the results that implies something about how that care is delivered and sort of the large quality context behind it.
CO-CHAIR HOMER: I think it is tricky. It's a very --

MEMBER JENKINS: I would like to clarify my question.

CO-CHAIR HOMER: Okay.

MEMBER JENKINS: I think I understand that when we are living in the scope of inpatient/outpatient care delivery. But when we chose the scope of this project, as a group, we also included these population-based measures which have poverty and disparities and parents and IQ and education and SES and a lot of things that are not in any way part of the process of care for practitioners.

And so that's where I'm confused. I understand your point when we are talking about inpatient care/outpatient care/ambulatory care, but not when we are in that other space. And this was presented as a population health measure, not as an ambulatory care quality measure.
CO-CHAIR HOMER: I think your point is well-taken. I don't think we are going to be able to come up with a bright line. I guess the way I think of it is if you are looking at something like school days missed, which is sort of an integrative measure of a whole variety of things, including, but not limited to health care, I'm personally more willing to sort of allow that kind of broad framing.

When you come up with really something that still sounds like a clinical measure, admission for UTI, now, that's my take on it.

MEMBER JENKINS: Got it. That's helpful.

CO-CHAIR HOMER: That's my take on it, I'm not saying that's -- but that's how I'm kind of differentiating these.

I think the other point that you have raised though that there are other technical reasons, like the broad age group,
which, you know, my wife being a judge reminds me that sometimes if you can make decisions on a narrow point, you don't go to the broad point.

I don't know if we use those same policies, but in this case, there is a narrow technical concern about the switch. Maybe we don't have to make the decision based on the broader one.

DR. WINKLER: Charlie, let me just follow-up with one thing. In terms of population health measures, this actually is a relatively new area that we are trying to address. Population health is one of the national priorities that was established.

We talked a bit about it in our November meeting when Dr. Bonnie Zell, who heads our population health efforts, talked about that. It is slightly different and we are actually learning and you are helping us learn how we are going to address some of these things.
NQF has previously endorsed some population-based measures, primarily the purpose of which was to provide context for the environment in which health care is being delivered. That was in our disparity sensitive project.

So I think that the issues you are bringing up are helping us learn the best approach to look at population measures, but there certainly is an audience and a demand for looking at it that way.

Also, I think that there is a sense that whatever happens at the individual patient/clinician interface rolled up to whatever larger provider group, those can be rolled up to what is going on in your local community. And rolled up, that would be the ultimate ideal way of being able to look at different levels of analysis and actually inputs and potentially actions at various levels.

MEMBER LIEBERTHAL: When I looked
at this measure, I said, it's interesting to
know, but I'm trying to -- and as I looked at
these other measures, especially the more
specific ones, such as this, I tried to look
at what conclusions can be drawn that would
lead to quality improvement.

And the implication of this
measure is that lower is better and for making
decisions for the individual child, lower may
not be better. So I think it is so broad that
the measure itself doesn't really add anything
to our ability to improve quality.

MEMBER MILLER: Charlie?

CO-CHAIR HOMER: Yes?

MEMBER MILLER: This is Marlene.

CO-CHAIR HOMER: Go ahead.

MEMBER MILLER: I would just add
my two cents. I think one of the
presentations I have on any area type level
measure is that, you know, the experience has
shown us that although measures get specified
for one thing, since there is -- once they are
approved in whatever group it is, there is no stewardship, if you will, of maintaining that. And so they have tended to then be rolled down, despite the fact that though, for example, if measures say this is not to be held accountable at an institutional level. They get rolled down because there is no one that sort of stewards -- controls, if you will, how entities use these measures.

So even though it's an area level measure, it always raises concerns when someone may start applying it at a health plan level regardless. And those, you know, kind of things have happened.

MEMBER FISHER: Can I add?

CO-CHAIR HOMER: Yes, please.

MEMBER FISHER: Can I add to what she was saying?

CO-CHAIR HOMER: Of course.

MEMBER FISHER: I agree wholeheartedly. And one of the -- also the fact is that because this implies that lower
is better, if people apply it that way, we may have an effect on quality that is decreasing it rather than increasing it.

And so it's an unintended consequence, but that's exactly what would happen, because it would apply across the board. And if you did it for younger children, it would be worse, I'm just assuming, than for older children.

So that's why I think the measure, you know, isn't a good one for what we want to do.

MEMBER RAO: Just to add, you know, along that same point, I think the measure could be acceptable and improved if it was just a narrow age group and had specific levels of severity.

I mean, obviously, for some kids admission is appropriate. And if they had said that they developed their measure around that criterion, it would have been acceptable, I think.
CO-CHAIR HOMER: Lee, did you also

--

MS. McELVEEN: Lee, did you have something?

MEMBER PARTRIDGE: I think Dr. Rao pretty much said what I was going to say. If this had been focused on teens, for example --

MEMBER RAO: Yes.

MEMBER PARTRIDGE: -- I would have had a very different reaction to it.

CO-CHAIR HOMER: Right. So I think just in the interest of keeping us moving forward, why don't we have a vote on the measure as is and then we can make recommendations to the steward if they choose to -- that our suggestion, whether we want to -- we can suggest to the steward that they modify the measure and we would be happy to see it again in the future, et cetera.

So why don't I call for a vote on it as is. So why don't we start with the negative, those who are opposed to endorsement
of this measure?

MEMBER MILLER: Charlie, my hand is raised if you're raising hands.

CO-CHAIR HOMER: Okay. Great.

DR. WINKLER: 14.

MS. McELVEEN: Is that it? Thank you.

CO-CHAIR HOMER: Any in favor?

MEMBER JENKINS: I would recommend with conditions.

CO-CHAIR HOMER: Okay. One recommend with conditions. Good. And were there any abstentions? Good. Okay. So, Kathy, do you want to tell us the conditions that you think?

MEMBER JENKINS: The conditions are that the measure be limited to population measurement only and we age and gender stratify.

CO-CHAIR HOMER: Do we want to hear from the stewards thought on that?

MS. McELVEEN: John, did you have
any comments about that measure?

MR. BOTT: You mean specific to the age and gender stratification?

MS. McELVEEN: Yes.

CO-CHAIR HOMER: Yes.

MR. BOTT: The measure is adjusted based on age and gender and stratification is possible at a number of levels, such as age and gender and the software.

CO-CHAIR HOMER: Okay.

MEMBER JENKINS: My understanding is the way the measure was put forward was rolled up, but it was commented that it could be age and gender stratified. So that was the purpose of my comment, was that it should only be presented age and gender stratified and not rolled up.

CO-CHAIR HOMER: Sounds like it's a moot issue. I think that reflects actually the sense of the Committee is that is how it should be done.

DR. WINKLER: I guess the question
is if that were to -- if they were to make
those changes, as Kathy suggested, would that
change the votes of the other Members of the
Committee from no to yes? It doesn't look
like it.

MEMBER PERSAUD: I would want to
see the age stratification.

MEMBER MILLER: Yes. This is
Marlene. I would want to see some data on
what that shows and the validity of it. I
know it changes the definition significantly.
You can't approve it and assume it still would
work right.

MS. McELVEEN: Okay. So we will
move on. I want to go to Measure 56. This is
the diabetes short-term complication rate.
Again, this was another measure where most of
the Members who reviewed and responded to this
survey voted not to recommend this for
endorsement.

A short description is just the
admission rate for diabetes short-term
complications in children ages 6 to 17 at per
100,000 population.

Comments?

MEMBER CLARKE: I just have one
comment. The discussion on page 3 of this
measure about the deliberations on the phone
suggest that a Committee Member recommended
adding first time admission for diabetes.
Actually, I was that Committee Member. And I
recommended excluding first time admissions
for diabetes.

And I believe Mr. Bott then said
that's really not possible because the coding
does not separate those two. So I just wanted
to clear that up.

MR. BOTT: That's a question for
AHRQ. Yes, the code doesn't offer that and
the measures that AHRQ developed, at the
present time anyway, didn't use the admissions
at a point in time. And that we are not yet
taking advantage of links to data sets where
we could perhaps link to previous admissions
and factor that into the denominator or exclusions.

The world could change in the future, but that's presently the data that we are constrained with.

CO-CHAIR HOMER: So are there any further discussions of this measure? If not, then we can just call for a vote. Well, I don't see any questions, so why don't we -- Kathy, comments?

MEMBER JENKINS: I guess the comment I would make is once again at the population-based level. The assumption would be that the rate of Type I Diabetes is relatively stable across population --

CO-CHAIR HOMER: Right.

MEMBER JENKINS: -- and across regions. That problem, with the validity of the measure, although real, may not actually be influential in understanding variation. I assume that's what the measure developer was thinking in terms of that issue.
CO-CHAIR HOMER: So following on that thought, if the prevalence of the disease and prevalence of new cases, incidents of new cases is the same across populations, then, in fact, variation and hospitalization rate would or could, in fact, be a reflection of care in the community.

MEMBER JENKINS: Yes.

CO-CHAIR HOMER: Because if the policies, in general, are to hospitalize, for example, first new diagnoses, then that should be stable across jurisdictions.

MEMBER JENKINS: And I would just add that that's a general principle for risk adjustment models where you are not always able to adjust for every important confounder. If an important confounder is relatively stable and your unit of measurement is large enough, that you could actually retain validity without needing to adjust for that unmeasurable confounder. And I see this as a general issue as opposed to a specific issue.
MEMBER McINERNY: Charlie, is it the place of NQF to recommend to the folks that are doing ICD-10 that they make two different codes? One for first time admission and one for subsequent admission for diabetes? Because that would be very helpful to us in the long run.

CO-CHAIR HOMER: I would let the people from NQF tell us that.

DR. WINKLER: We can certainly include that as a recommendation, getting that to the appropriate audience might be challenging, but we can give it a try.

MEMBER McINERNY: Thank you.

CO-CHAIR HOMER: So why don't we call for a vote then on this measure? So again, this is the measure of admission rate for diabetes in children age 6 to 17 per 100,000, so it's reported only as a population measure, that is what it is specified as.

So all those, we will stay with the negative, who recommend not endorsing?
MEMBER MILLER: I've got my hand raised, Charlie.

CO-CHAIR HOMER: Okay.

DR. WINKLER: 10, 11.

CO-CHAIR HOMER: I think I'm going to vote for this one. All those in favor?

DR. WINKLER: One, two, three, four. Are there any abstentions? Did we catch everybody? Microphone.

CO-CHAIR HOMER: Let's go back.

Let's go back to the --

DR. WINKLER: Yes.

CO-CHAIR HOMER: -- other measures. The measure fails.

MS. McELVEEN: So we are going back to Measure 55. This is measure gastroenteritis admission rate.

Again, the age group is 3 months to 17 years. And based on the Committee Members who reviewed this measure and provided their votes, six recommended it for endorsement, two did not and there were two
that recommended it with conditions.

So this was more favorable, but I can open it up for more comments.

CO-CHAIR HOMER: Ellen?

MEMBER SCHWALENSTOCKER: So my only concern with this measure, and I like it better than the other two, but, would be what Marlene raised earlier, which is the potential for misuse. So if I could be assured that it was just going to be used at the population level, I would feel comfortable with it.

But it seems to be a slippery slope out there that sometimes measures intended for one thing get used for another. And my only worry is on unintended consequences, i.e., keeping kids out of the emergency room when that may be the only place they can get care.

MEMBER McINERNY: This is one where I think there is a place where the measure can be useful in spurring QI activities, because among the reasons for
admission are inadequate use of oral rehydration, not having short-term holding areas.

And I think that if this did trickle down to the health plan or hospital level or even provider level, that perhaps it would induce some change in behavior that would be a positive effect. So on that basis, I think that this is a useful measure.

MEMBER MILLER: Charlie?

CO-CHAIR HOMER: Yes, go ahead, Marlene.

MEMBER MILLER: This is Marlene. I need to say my only experience is that I work in an acute care clinic. I have seen the exact opposite where it would not be good if it trickled down, in that often times part of the admission for this are very complicated with psychosocial issues and parent limitations and fragmented care and lack of consistent caregivers.

And in that case, it is the right
thing, from a QI purpose, for a hospital to admit that patient for the gastroenteritis which comes up a lot and my population is, you know, 85 percent is not more Medicaid. So at least in my own experience, I'll say that it is often times the right thing for the hospital to actually admit the patient, because of complicated social circumstances that have failed out patient care.

CO-CHAIR HOMER: Okay.

MEMBER JENKINS: I would just point out that at the population level, that is still potentially preventable, so this is a general concept that we have been discussing in all of these places.

MEMBER MILLER: However, I would say right back when you say that the population level -- the interventions at hand, it just get rolled out institutional level. For me, to impact the psychosocial environment are just not there. That goes right back to my beginning point when we say we are going to
endorse measures.

I would like that all the measures have a tool kit that you can hand folks. No one likes to perform bad. People want -- if they are going to have the condition, give them the tools so that they know what to do with it.

CO-CHAIR HOMER: But in this case, there actually are -- I mean, there are -- there actually is a tool kit. Now, again, part of the tool kit needs to be broader. In other words, there are tool kits for oral rehydration and management thereof, you know, AP Guidelines, et cetera, around that.

I think the solutions we are talking about for this would be also broader, like some of the community transformation activities that are written up in health reform. But I think at least it is within the range of concept that one can reduce at a community level hospitalization for gastroenteritis, you're right.
It would be unfortunate. You wouldn't want the adverse -- you wouldn't want a clinician at the front lines dealing with an individual patient that they are concerned about to have pressure put on them from hospital administration, for example, that the hospital would be dinged if they make the right decision and admit a patient.

And that's what I hear from your concern, which, you know, is a reasonable unintended concern. But at the population level, if you were comparing, you know, inner city Baltimore to inner city Harlem, you know, you would want to be able to compare.

You know, and again, I tried to pick communities that would be of comparable demographic status. You would want to be able to compare how effective one community was compared to another in their ability to prevent something like this.

MEMBER MILLER: I totally agree, Charlie. The problem is always that once it
is approved and out there, there is not
stewardship of how it is applied.

We may just end up getting rolled
down to a health plan at institutional level.
We may actually have negative impact on
quality of care.

CO-CHAIR WEISS: Stepping back
just a minute. I'm wondering if what this is
leading us to is a discussion about
presentation and maybe putting a tag line or
a footnote or some sort of statement together
with these population measures that makes it
abundantly clear that we intend for them to be
used in that way and in that way only?

CO-CHAIR HOMER: Yes.

DR. WINKLER: That's certainly a
very feasible thing to do when we write the
report, put it in a separate section of its
own labeled population measures and describe
the reasons for which they are approved.

Again, we can make that abundantly
clear in terms of the presentation as a
reflection of what your recommendation is and
limited to.

MEMBER McINERNY: Two points.

Number one, there is an upstream preventive
measure that would also reduce hospitalization
and that is the use or rotavirus vaccine and
how well that is being used.

CO-CHAIR HOMER: Well said.

MS. McELVEEN: Yes.

MEMBER McINERNY: Then the other
point though that I -- I think people may be
alluding to, but I want to make sure I
understand it correctly is, is there a concern
that a health insurance company would say,
hey, NQF has said children with vomiting and
diarrhea should not be admitted to the
hospital, therefore we will deny this
admission.

Is that sort of where we lose
control?

MEMBER MILLER: Yes, that's a
great example.
MEMBER McINERNY: Insurance companies have been known to do that.

MEMBER JENKINS: But we are not going to solve everything here at this Committee.

MEMBER McINERNY: Right.

MEMBER JENKINS: I think that the idea though, and I had asked this on the phone, Charlie as my specific question to you about these measures, was if they were being proposed as population-based measures, would the endorsement be limited to the use as a population-based measure?

Because I can think of 1,000 confounders and problems if they get down to too small buckets of patients. This is only one.

DR. WINKLER: Yes. The endorsement can be limited to the mass population-based measures only certainly. I mean, we have had other measures that are appropriate only at certain levels of analysis.
and that's what the endorsement is limited to.

MEMBER SCHWALENSTOCKER: So then

would that be a recommend with condition or is

that just okay?

DR. WINKLER: These are specified

as population level measures. So all you are

saying is yes and that's how that should be

used and that's the limit of our

recommendation.

CO-CHAIR HOMER: Well, one last

comment, because I'm conscious of the time and

how much we have to do over the next two days.

So go ahead, Lee.

MEMBER PARTRIDGE: I don't want to

prolong this discussion, but I did notice the

comments in the materials you sent out talked

a fair bit about the rotavirus and I don't

know that issue. I'm just wondering if it is

worth exploring for half a minute more what

its impact is and how it is mixed in here.

Is there a separate measure out

there of the use of rotavirus?
MEMBER PERSAUD: There isn't --

MEMBER PARTRIDGE: I don't think --

MEMBER PERSAUD: -- a separate measure that we know of.

MEMBER PARTRIDGE: That's what I thought.

MEMBER PERSAUD: What the literature shows is that since the inception of the virus now, I think, at least two full years, that admissions for rotavirus, gastroenteritis in toddlers, in particular, has precipitously dropped and that is the expected effect of the vaccine.

MEMBER PARTRIDGE: So presumably, this is one case in which we might want to have some recommendations of the Committee down the line?

DR. WINKLER: Actually, the rotavirus is included in the childhood immunization NQF measure. I mean, NCQA measure that is NQF-endorsed. So it has been
included since the vaccine has become available. So it is already included in our childhood immunization measure.

MR. GEORGE: Could I make one last comment just addressing Tom's point there about insurance companies using this measure inappropriately?

I mean, do we need a statement that says, for example, these measures are not intended to be used as a clinical practice guideline or as a clinical algorithm or is there enough in the description of the measures to counteract that?

DR. WINKLER: You're not talking about something that is specific to these measures, but is something that is ubiquitous around performance measures in general. And for the most part, usually the discussions are talking about that the targets for any of these measures are never zero or 100, whichever, however the measure is crafted, such that there is an acceptable level.
What we are looking for is minimizing variation, minimizing extreme outliers and trying to bring everybody to whatever that acceptable appropriate level is. And so it's not a black or white all or none thing.

And that tends to be the discussion that pervades all of performance measurement.

CO-CHAIR HOMER: Did you have a comment? No, okay. So why don't we vote on this measure? I'll follow the same process, just so people don't get confused.

So we will start with the negative, that is all those opposed to the endorsement of this measure signify by raising your hand or saying something on the phone.

MEMBER MILLER: Something on the phone.

DR. WINKLER: Marlene, your's is a no?

MEMBER MILLER: Yes. Thank you.
CO-CHAIR HOMER: Anyone else no?

Okay. All those in favor of the measure?

DR. WINKLER: 13, 14, 15.

CO-CHAIR HOMER: Good. And no abstentions then. Good.

MS. McELVEEN: Moving on. The last measure in this set is the asthma admission rate measure.

Again, the response to this was favorable for endorsement. This is the asthma admission rate for children ages 2 to 17. And I'll open it up for comments.

CO-CHAIR HOMER: Any comments on this measure or you feel like we have covered the general discussion pretty well with the gastroenteritis framing? Many of the same concerns and issues.

Well, seeing no discussion --

MEMBER SCHWALENSTOCKER: Oh, one thing.

CO-CHAIR HOMER: Ellen?

MEMBER SCHWALENSTOCKER: The
measure harmonization issue, can somebody recall what that issue is?

PARTICIPANT: It's age.

MEMBER SCHWALENSTOCKER: It's age?

Oh, beginning at age 2.

DR. WINKLER: Yes, most of the measures that offer asthma begin at age 5, rather than at age 2.

CO-CHAIR HOMER: So is there any way to address that or are we stuck with what we have?

DR. WINKLER: Yes, let's ask John Bott from AHRQ. Why was age 2 chosen for this particular measure when, typically, measures of asthma begin around age 5?

MR. BOTT: Yes. Unfortunately, I'm not a clinician to be able to really address that, but that's Patrick Romano's question. And we didn't think there would be much discussion today, so I told Patrick he wouldn't need to participate today. So I'm sorry, I can't personally answer that
question.

MEMBER JENKINS: I would imagine the issue, Charlie, I assume you're going to say this, is that there is sort of a conventional wisdom that you can't diagnose asthma before age 2. That line is often drawn and I would imagine the people who came down on the 5 year age range said, well, there is some wiggle room between 2 and 5, so let's cut it clean at age 5.

And you are just seeing both sides of that in the older measures versus this measure.

MEMBER FISHER: Or somebody got a 2 mixed up with a 5.

CO-CHAIR HOMER: No, I think the clinical -- so I think in favor of it as starting at the younger ages. Hospitalization for asthma is, you know, very high at younger ages and decreases as you get older. So if you are trying to capture the largest number of hospitalizations, you don't want to miss
the 2 to 5 year-old slot.

On the other hand, the clarity of the evidence about the efficacy of, for example, anti-inflammatories, the older ones you hit the age 5 and up, you are clear you are dealing with the inflammatory disease. You are less confused with some of the others, with small airways, et cetera.

So I think, you know, there is an intersection here between crispness of diagnosis and efficacy of therapy with the older kids and the burden of disease which is in the younger kids. And that's my guess is why they ended up including the 2 to 5 year-olds in this and not into the more clinically-driven measures.

Allan, do you want to comment?

MEMBER LIEBERTHAL: Yes. Well, one of the reasons that the NHLBI and most asthma guidelines start at age 5, one of the reasons is that's about the earliest that you can do pulmonary function testing, which the
allergists really believe in, whether they need to assure that or not, I don't know.

The other thing is I think that under age 5, you are opening yourself up to huge coding errors as to what was the real reason for admission.

So any child who wheezes under age 5 might be diagnosed as asthma, whereas wheezing is a secondary finding due to another pulmonary problem under age 5. So I think it is much -- even though it excludes a whole large group of children, the convention of over age 5, I still think should be used.

CO-CHAIR HOMER: Kathy?

MEMBER JENKINS: I would just point out that this is again very similar to the Type I Diabetes issue. I said before when you are in the population-based arena across large boxes of patients, that essentially misclassification bias, which is what you are alluding to on the 2 to 5 year-olds, if that was equivalent across the country, for
example, or large geographic regions, then the variation -- you could still understand variation, despite that limitation, that real measurement limitation that you are alluding to.

MEMBER LIEBERTHAL: I don't think that anybody has shown that it is consistent across the geographic country or in the health care system. I think that academic centers may code one way and the community hospital another way.

CO-CHAIR HOMER: It's a population measure derived from discharge -- hospital discharge data, right? I mean, that's where you get it.

MEMBER JENKINS: Could we ask AHRQ what they consider to be the geographic unit of a population for the purposes of this measure? Is it a state? Is it a region? I assume it's not an institution.

MR. BOTT: No, it's not an institution. It's typically a state, county,
something else that would end up at the
appropriate levels or, of course, with the
National Health Care Quality Reorganization.

CO-CHAIR HOMER: Okay. I think it
has been another excellent discussion, as they
all have been. Why don't we move forward with
the vote?

So all those, again, opposed to
endorsing the asthma measure as a population
measure? All those opposed? Three.

DR. WINKLER: Marlene?
MEMBER MILLER: Oh, sorry, I was
on mute. I oppose.

DR. WINKLER: Okay.

CO-CHAIR HOMER: Four.

DR. WINKLER: Four nos.

CO-CHAIR HOMER: All those in
favor of approving, endorsing the measure?

DR. WINKLER: One, two, three,
four, five, six, nine, ten. Ten yesses.

CO-CHAIR HOMER: So 10 to 4. Any
abstentions?
MEMBER SCHWALENSTOCKER: I'm not abstaining, but I would recommend with the condition that the age issue be looked at.

CO-CHAIR HOMER: All right.

MEMBER FISHER: That's a concern I have, too.

CO-CHAIR HOMER: So from a process perspective, the Committee, at this point, is recommending that it go forward for endorsement. The notes are always reflected when that goes forward, so that both people will see the vote and they will also see the concerns that were raised, including the recommendation. So I think that's good.

MS. McELVEEN: Do you want to vote on that recommendation?

CO-CHAIR HOMER: I don't think we need to. Okay. Well, congratulations. This is good. We did four. We closed it. The first are always the hardest.

MS. McELVEEN: They are.

CO-CHAIR HOMER: So, Nicole,
should we move into the clinical measures or take a break? How do you want to proceed?

MS. McELVEEN: Do people need a break? Does anyone feel like they need a break? Okay.

CO-CHAIR HOMER: I would propose a five minute break.

MS. McELVEEN: Okay. We can take a five minute break.

(Whereupon, the above-entitled matter went off the record at 10:24 a.m. and resumed at 10:35 a.m.)

CO-CHAIR HOMER: Well, why don't we reconvene? Thank you for allowing me to replenish my coffee cup. I do, well we all live on caffeine.

So now, we are going to move from the population measures to some of the more clinically oriented measures. And the first group is the clinically, what is called, the clinically-based measures. So these are the ones that were -- whoops, am I --
MS. McELVEEN: That's 27, 28 and 29.

CO-CHAIR HOMER: 27, 28, 29, right?

MS. McELVEEN: Yes, that's the old agenda.

CO-CHAIR HOMER: Oh, I have the wrong agenda in front of me.

MS. McELVEEN: Sorry.

CO-CHAIR HOMER: I'm sorry.

MS. McELVEEN: My apologies. I copied the wrong agenda this morning. The first set of measures will be Group 2. It's the Questionnaire Survey Measures.

Does everyone have a copy of the newer agenda, updated?

CO-CHAIR WEISS: No, it's not on--

MS. McELVEEN: It's not on the flash drive.

CO-CHAIR WEISS: It's right here.

MS. McELVEEN: Ashley, do you have more hard copies?
MS. MORSELL: The ones we handed out are blank.

MS. McELVEEN: It was the wrong one. You can use that.

CO-CHAIR HOMER: That's still the wrong one.

MS. McELVEEN: Yes, sorry. That's my copy. You can use that.

CO-CHAIR HOMER: So we are now going to the group -- I stand corrected, or I sit corrected. It's Measure 034, which is the National Survey of Children with Special Health Care Needs 2005/2006 and the quality measure component thereof.

Do we have the steward on the phone?

MS. McELVEEN: Do we have anyone?

CO-CHAIR HOMER: That would be Christy.

MS. McELVEEN: Yes.

CO-CHAIR HOMER: Do we have anyone from CAHMI on the line?
CO-CHAIR HOMER: Marlene, are you still there?

MEMBER MILLER: I'm here.

CO-CHAIR HOMER: Oh, good.

MS. McELVEEN: Any other measure developers on the line? They have a correct copy of the agenda, so they are aware. So we will just go ahead and get started.

CO-CHAIR HOMER: Okay.

MS. McELVEEN: We will just go ahead and get started with that, this first group of measures. Again, this is Group 2.

PARTICIPANT: So it's 34?

MS. McELVEEN: So we are starting with Measure 34. The reviewers were Bonnie Zima, Jane Perkins, Nancy Fisher and Ellen Schwalenstocker. And just as a separate note, this first measure that we are looking at, Measure 34, the National Survey of Children with Special Health Care Needs Quality Measures, within that particular larger survey, there are individual, smaller measures
that are comprised of the larger survey measure.

Two of those were also submitted individually. And those were 35 and 37. So just so you know as we are reviewing them, when we get to those, 35 and 37, those measures are actually a component of that larger survey measure.

Projected on the screen is feedback from the reviewers, their ratings of the sub-criteria and also any comments or concerns that were raised while they were reviewing this particular measure. And this information is also on your thumb drive.

Let me just quickly read a description of the measure just to introduce it a little bit. This is the National Survey of Children with Special Health Needs. It is a population-based survey designed to assess how well the nation and each state meet the Maternal and Child Health Bureau's strategic plan goals and the national performance.
measures specifically for children with
special health care needs.

The questions address a variety of
physical, emotional and behavioral health
indicators and measures of children's health
experience with the health care system and ten
of these measures are directly focused on
children's health care quality.

Do we have any of the assigned
reviewers who want to take a first stab at
kind of reviewing their initial evaluation of
the measure?

CO-CHAIR HOMER: Thank you, Ellen.

MEMBER SCHWALENSTOCKER: I have
not had a chance to sort of synthesize the
comments, so these are just sort of my
perceptions.

But I really had trouble with this
one, because I was trying to figure out how to
evaluate the overall instrument. You know, it
seemed to me, and I honestly haven't gotten to
look at the details for the subgroups 3 and 4,
but it seemed to me throughout, a number of individual measures were pulled out of this, so I had trouble, you know, sort of figuring out what kind of context to put this in.

But I did have a couple of bigger concerns with the survey itself. One is, I would really like to know more about what we know about the response rate and potential for response bias, because it is probably one of the longest surveys I have ever seen and a number of quite sensitive questions.

So I wondered about the dropout rate and then I also wondered about how accurately we know that the family member can respond to some of these questions. Like how many hours did you spend caring for your child over X time period.

So I had difficulty trying to figure out how to assess the questionnaire overall and found myself wanting a lot more information over, you know, just what we know about response rate and accuracy of reports.
MEMBER FISHER: You make me feel so much better. I agree with her that I thought the survey was quite long and wondered if somebody was even using it, whether you could get enough people to participate.

But I felt that the survey was not what was needed here. What we needed was specific measures. This is a good way to, if you are using a survey, to gather information. And then after you gather the information, because of the information you have in the survey, you may put out some measures you want from your analysis of the survey.

So I didn't think that that really fit in with what we were doing.

MEMBER JENKINS: Is it being put forward as a population-based measure or what's the unit of analysis?

MEMBER SCHWALENSTOCKER: Charlie, if I could add one more thing? I mean, it looks to me like it is pretty widely used. So I guess I would want --
CO-CHAIR HOMER: This is --

MEMBER SCHWALENSTOCKER: -- more information about how it has been used and how useful it is. And I just couldn't assess that from the materials.

CO-CHAIR HOMER: Yes. So I'm concerned that Christy Bethell, the developer, isn't on the phone, because this is extremely widely used. I mean, it is, for example, what every state at the population health level for the State Title V Programs, this is how they are assessed, is they are assessed on what proportion of children have a medical home? What proportion of children have access to health insurance? What proportion -- you know, how satisfied are parents with the services they receive?

Those are all derived from this measure.

CO-CHAIR WEISS: Let me add that this survey is an outgrowth of legislation that was enacted in the late 1980s that
imposed upon Title V Programs for the first
time a requirement that they obtain
information on patient care that is delivered
through their program.

And the way it is structured is
that there are a series of data elements that
they look at and states have certain items to
which they must respond and others that are
available to them on a voluntary basis.

So it is widely used. The data is
being collected. How well or, you know, how
consistently across the country is open to
question. But the data is there and there is
legislation that lies behind that requires it
at this point.

Now, it may be -- I mean, this is
an old instrument and an old directive and it
may be that this is one of the areas that we
should point to for HHS to take a fresh look.

MEMBER FISHER: You know, but
going along with what you said it is being
used, then to me, like you said, there is
certain things you have to answer and you have
to do. What I'm saying is you have this
instrument. It is being used. So you look at
it and you say okay and you look across the
country and you see that children with special
health care needs, they don't have a medical
home.

Okay. Then, to me, you put a
measure. So you find out what is going on
with the kids, why don't they have a home?
And so, to me, it's gathering a lot of
information, but, in itself, it has got a lot
of measures in it.

CO-CHAIR HOMER: Right.

MEMBER FISHER: And it's just too
big, too broad, but it's something that I
think that we can use, because we have
information. To me, it's the information for
gaps or what you want to make improvement on
and what you want to then go down and be
specific and hone in on.

So that's why I said I didn't
think it fit in with what we were doing. And they did submit the other measures, see, and that makes sense to me.

MEMBER LIEBERTHAL: I had the question, because this applies to Group 3 also that I was on, is why did they submit the whole survey as a measure and then pick out a couple of the questions also as measures? It would appear to me that each of these questions should be evaluated on their own merits, because some of them may be valid for quality measures, whereas others may have problems that would make them not acceptable. So I don't know if we have the option of separating them all out or just take the two that they chose to separate out.

CO-CHAIR HOMER: Kathy?

MEMBER JENKINS: Allan, I agree in terms of this being exactly the issue in one of the measures in Group 3, but I don't think it is the whole survey.

CO-CHAIR HOMER: No.
MEMBER JENKINS: I think that they have chosen 15 individual items, which they regard as the quality measures on the entire survey. They are though, to your point, proposing all 15 as a group. And when I tried to do that on the other survey, I had the exact same issue where I had to -- I couldn't really consider them as a group, because my answer depended very much on which of the 15 or however many it was in the other survey we were referring to.

CO-CHAIR HOMER: So let me ask NQF staff. I mean, another survey which is broadly endorsed by NQF is the CAHPS Survey. The same concept though is that really what you use on the CAHPS Survey is not CAHPS, but you use the variety of domains and domain scores and things like that.

But if I understand correctly, CAHPS itself is endorsed rather than the specific domains and reports that come out of it. Tell us how that was handled.
DR. WINKLER: Okay.

CO-CHAIR HOMER: Because I would think this is a pretty similar kind of issue.

DR. WINKLER: Yes, yes. The problem with what you are saying, Charlie, is the two don't separate very readily, because the instrument is the tool, the data gathering tool. And you can't use an alternate tool to create the summary results of the CAHPS Survey, and there are several of them.

So the measure is actually those results that are reported, but the tool is an, you know, inextricable part of the measure in how to collect the data to create those summary results that are the things that are posted and published and all of that.

So similarly, I think, you can look at these as you have a tool versus you have the information that you would report about whatever as more of the measures. But the two have to be related, because it's not as if you can use another instrument or some
alternative data collection method to get the
information to create those measures.

MEMBER FISHER: Is the idea to
endorse a tool, so that everything is
consistent? I mean, you know, so that
somebody else doesn't come up with another
tool?

DR. WINKLER: Right. I think that
heretofore what NQF has done is endorsed tools
sort of as part of measures that are well-
defined because we want standard measures that
can be used to allow the comparability.

When it comes to survey tools, you
pretty much end up endorsing the tool, but
that isn't our primary focus to endorse the
tool. It is to endorse the measures that are
derived from that data collection methodology.
Okay.

MEMBER FISHER: Well, I feel like
I sort of screwed up, because I should have
looked at each one of the individual measures
for the endorsement.
DR. WINKLER: You know, the question I would ask on this one is using the tool as presented here with the multiple parts, is there a summary result that comes from it that is the measure?

I know, what would you publicly report from this?

MEMBER JENKINS: Well, I think that's what they have tried to do. They did it in two ways. For certain individual components, they created what they are considering to be a summary. And in this case, we have to say outcome measure.

The one that we are working on here though, there is no summary measure and it does appear as if there is 15, some of which on this instrument and the other one, I regard as structure process and some I regard as outcomes and some probably could be either. So we have that additional problem.

MEMBER SCHWALENSTOCKER: You know, that was actually another point of confusion
for me in that they talk about 15, but then listed are actually 22 measures. So I wasn't sure. I just wasn't sure how to assess this tool.

MEMBER JENKINS: I personally would take the position that we cannot endorse all 15 or 22 or however many it is for Group 3 all as one, that we can only endorse them at the individual level, that's my personal recommendation.

MEMBER FISHER: I was going to say the same thing that we would have to take them, you know, at another session or something, divide them up and look at them and endorse certain ones for the survey if that's what they want.

DR. WINKLER: These have been submitted to us as those individual measures, however many there are, as well as the tool. And it is unfortunate. Are we expecting Christy so she can answer the question of why the tool is also submitted as well as the
measures derived from it? I think that's an important issue to resolve.

MEMBER FISHER: All of the 22 measures have been submitted.

MEMBER JENKINS: It isn't submitted. It's only for -- if you look at the numerator, that's where you can figure it out.

MEMBER FISHER: Oh.

MEMBER JENKINS: So I'm looking on the Numerators 2-A, 2-1, I think. Well, that's the algorithm. Numerators comprise, that's where you can figure out what their measures are. And to me, it looks like a group of measures. It doesn't look -- it looks like 15, but maybe if you counted them it's 22.

CO-CHAIR HOMER: Right.

CO-CHAIR WEISS: I think this is a different population. 22 of all children were served by time, whereas children with special health needs in the population here.
CO-CHAIR HOMER: No, you turned it off.

CO-CHAIR WEISS: That's where the 15 comes.

MEMBER JENKINS: That's true in the other survey, but this is the special health care needs survey.

CO-CHAIR HOMER: Yes, this is the National Survey. And then it's this --

MEMBER JENKINS: The other one, there is that issue where it is stratified by special health care needs versus not.

CO-CHAIR WEISS: Right. 33 goes to the issue of all 22?

MEMBER FISHER: Is that 33?

CO-CHAIR HOMER: 33 is Group 3.

DR. WINKLER: We need Christy, right?

CO-CHAIR HOMER: Yes. I think the short answer is we need Christy. I mean, these are 15 more or less performance measures for children with special health care needs.
based on items from the National Survey for Children.

MEMBER FISHER: Right.

MEMBER JENKINS: Right.

CO-CHAIR HOMER: So there is no way to calculate these without the National Survey.

DR. WINKLER: Right.

CO-CHAIR HOMER: But I think what I'm hearing from the group is (A) a desire to have more information on the psychometric properties of the instrument so response rates, et cetera, et cetera, which I suspect will be readily available.

And then the second is people really want to know more specifics about each of these items or each of these. Some of these measures are from single items. Most of them are actually composites from several items together. And that's what you would like to know.

MEMBER ZIMA: There is also kind
of a prematurity to thinking about this as an indicator quality, I think. And maybe this is something to put on GAP. There is also a heterogeneity around CSHCN definition. And so it's sort of you have sort of heterogeneity in the numerator whether it is type of service, unmet need or need for service.

And then you have this heterogeneous group and I would like to propose that, you know, as we think about future steps, you know, perhaps we need to be also teasing out what this CSHCN Group really is.

CO-CHAIR HOMER: But I guess I would contend we could certainly discuss that. I would contend that this measure reflects 15 years of discussion and, basically, consensus within the maternal child health community around what comprises children with special health care needs and this measure. The screener was really designed to reflect that consensus definition.
So for NQF to sort of deconstruct that would be difficult.

MEMBER McINERNY: You don't want to go there.

CO-CHAIR HOMER: Yes, I wouldn't recommend it.

MEMBER FISHER: I agree with you that there is some heterogeneity around it, but it has been defined for the people that are going out and they are looking at this for like your Medicaid population and stuff as the person who has done that.

So it has been defined. They have a special thing for it, especially the people that audit the Medicaid programs and for the Balance Budget Act that was passed. They have specific things that they put into a group. It's still sort of a heterogeneous group, but it's defined that way.

CO-CHAIR WEISS: But you are quite right, Bonnie. It is a very broad definition.

CO-CHAIR HOMER: Okay, yes.
MEMBER JENKINS: I saw that issue as affecting the actionability of the findings.

DR. WINKLER: What I'm hearing from everybody is this measure actually, you can call it anything you want, but, is a compound measure, so that a result from it would give you 15 separate reports out.

CO-CHAIR HOMER: Right.

DR. WINKLER: But as a single measure, all 15 would be required. And so that would be the output. It's not a composite measure, because those 15 aren't in some way summed up or aggregated for a single. So I don't know what you would call it, but it has these multiple -- it's a multi-part measure for sure.

And I think the question for the Committee is starting to address the issues that Kathy and Ellen and Nancy have brought up is since you would be obligated to include all of these parts if we were to endorse this
measure, is what you would want to do?

Do you have concerns about certain parts of it versus others? Realizing that there are other measures that are more singles that they have also submitted using the same tool.

CO-CHAIR HOMER: Tom?

MEMBER McINERNY: Yes. As I look at these 15 measures, I think, all except perhaps that last one are really process measures.

DR. WINKLER: Yes.

MEMBER McINERNY: And it's only the last one that says on that health care needs that is an outcome measure, in my mind, the rest are all, you know, do you have insurance? Do you have a physician? Do you get family-centered care?

CO-CHAIR HOMER: But --

MEMBER McINERNY: So those aren't really outcomes.

CO-CHAIR HOMER: -- I would beg to
differ or, at least, suggest that they could
be viewed either way. Just like one could
say, for example, hospitalization for asthma
is a process really. It's not an outcome.
That is you are doing something to a patient.

Having a medical home can be
viewed as, I mean it can be viewed, as an
outcome. Having effective care coordination
can be viewed. I mean, those things we
included in our solicitation health processes
as potential outcomes.

So I think these are on the
border. These are -- again, we can challenge
this, the Maternal Child Health Bureau's
Division of Children with Special Health Care
Needs has six aims that they have articulated
through a public process for children with
special health care needs, that is that all
children should have -- all kids with special
health care needs should have insurance, that
they should have a medical home, that care be
accessible, you know, et cetera. And it
should be that care be culturally competent.

I'm forgetting two, because of my lack of sleep.

But basically, those the Maternal Child Health Bureau would consider, quote, outcomes. This group, if you want, I mean we can call them processes, but I think these are on the fence between processes and outcomes.

MEMBER DOCHERTY: I think especially for this population that they are outcomes.

CO-CHAIR HOMER: Yes.

MEMBER DOCHERTY: They are important outcomes.

CO-CHAIR HOMER: Okay. I guess I think -- I hate to disrupt the process because it looks like survey measures are very substantial, I think we need the steward to actually have a fair conversation around this and just wonder if we can move to some other? If we could sort of table some of this conversation until we can get Dr. Bethell on
the phone and then come back to a broader discussion of these? Is the Committee willing to do that and staff okay with that?

DR. WINKLER: What do we know about her availability?

MS. McELVEEN: She will call in. We are expecting, obviously, for her to call in. There are several staff Members that are sort of staggering their time to call in to try and be here available for us. So we are trying to get in contact with them. We have emailed them, so hopefully they will be calling in shortly.

My suggestion was to move onto Measure 43. The measure developer is here in person, but I just saw him step out for a second.

CO-CHAIR HOMER: But what usually happens is we would have one of the reviewers, right, discuss it and then round him up.

MS. McELVEEN: Absolutely. So what we are going to do, Measure 43 is still
a part of Group 2. It is titled the Pediatric Symptom Checklist. And I'm going to quickly pull up the feedback from a few of the reviewers who were able to provide us feedback on the sub-criteria for this measure.

Let's see, all righty. And this particular measure's description is a brief parent report questionnaire that is used to measure overall psychosocial functioning in children from ages 4 to 16 years of age. It was, it looks like, originally developed to allow pediatricians and other health professions to identify children with poor overall functioning who are in need of further evaluation or referrals.

In addition to the original 35 item parent report form, there are now other validated forms and translations, it looks like, of this particular survey.

I would like to just open it up to Michael Murphy who is part of the Measure Development Team, if he had any comments,
prior to the Committee discussing the measure
or just -- okay. So we will open it up to the
group for further discussion.

It looks like again this is, it
looks like, another survey questionnaire type
of measure. So I think it might be worth kind
of going through importance a little bit
first. It looks like the Committee is on the
fence in terms of this.

MEMBER JENKINS: Can I ask Michael
a question? If he could just explain why it
is an outcome measure, I think contextually
that would be really helpful to us.

DR. MURPHY: I think that --

CO-CHAIR HOMER: Just come up and
use the microphone, please.

MEMBER JENKINS: There is a seat
right up here, if you would like to come down.
I'm not so sure how you are defining the term
Health Outcome Steering Committee, so I think
we have been discussing a lot of issues around
that definition. So I just wanted to hear
your perspective about the checklist as an outcome measure.

CO-CHAIR HOMER: So again, I think in the context, if it was initially designed as a screening test, so something that might indicate there was a problem, now, it is being proposed in the sense as an outcome measure that is something that is really reflecting that there is a problem as opposed to there is an increased likelihood compared to baseline.

So I think to put a finer point on it, can you talk a little bit more about your level of confidence and the abnormal screening on one or more dimensions of the PSC actually as an outcome measure that would be important to track on a population basis or to indicate one population is more healthy or less healthy than another population?

DR. MURPHY: You're speaking so well, I think I should just have you keep going, but actually it's a great question, because it was designed as a screen, but
because it is used so much, it is being used as an outcome measure.

So you know, we don't have any --

CO-CHAIR HOMER: Do you have any evidence yet from the literature? I guess this goes really to the validity more than the importance character, but the validity that an abnormal screen is associated? And can you talk about the predictive value positive/negative sensitivities, specificity, you know, or conceptually, but something along those lines that says your level of confidence?

People are using it, but just because people are using it, doesn't necessarily mean it is the right thing to do. So just talk a little more about the scientific basis for that.

DR. MURPHY: Yes. So to go back and forth, I read some of the comments, I guess, from last night. Our confidence in it as you and I discussed on the break, it's
being used in Massachusetts and, you know, we have some data. One is a published study from Cambridge 2009, a relatively large population of about 1,000.

And then we have data from the State of Massachusetts, which is, you know, tens of thousands of cases that we have seen. So in terms of its validity as something that can pick up kids -- one of the reviewers asked what's the evidence that positive screens lead to referrals?

And so now, both in a sample of 1,000 Cambridge and in the State of Massachusetts as a whole, we have data that shows that positive screens are referred. So in terms of the usefulness of it, I mean, that's sidestepping the issue of validity.

So is that a good start or you want more on the positive predictive validity?

CO-CHAIR HOMER: I mean, we need, I guess, the threshold. Maybe we got out of -- the threshold question is important and I
actually do see that some of the reviewers had concerns about importance. That is can you talk a little about, this should be a medium -- from my perspective, this is a medium speed, fast ball right down the middle of the plate.

It should be able to wallop this one out there, but editorial judgment.

Can you talk a little about what the evidence is that psychosocial issues are broadly defined, significant problems in child health and that this measure -- and that there is a gap between current practice and what, you know, is a desired practice? Because that -- again, I'm seeing the scores on this are partially and minimally, that is nobody felt that at least the report that was submitted clearly indicated that they were convinced that this is a particular issue, psychosocial problems, and the current practice is inadequate to identify it.

DR. MURPHY: So yes, I thought -- I was surprised when I talked to Mike Jellinek
a little bit about it, you know, from our point of view. And we think from National Standards point of view, psychosocial problems broadly defined are a hugely important issue.

So it's an aspect of medical care for kids and for adults that is left out, has traditionally been left out and there is tons of, you know, high level legislation and Committee recommendations that are being included as a part of routine health care.

So anyway, so there is a large literature and a long term of literature that says psychosocial problems broadly defined are very important, both for physical health and for life outcomes.

CO-CHAIR HOMER: And the current practice?

DR. MURPHY: Thank you. And the current practice remains. You know, Tom McInerny is here. He as a part of a study a decade ago that looked at Jane Costello's data from two decades earlier and Barbara
Starfield's evidence from three decades earlier that psychosocial problems are routinely under-identified and under-acted upon.

So it's a continuing problem that legislation has sought to address and the PSC is a well-validated way to identify the problems and now we seek to actually get more referrals.

You know, some of the questions you were asking before about sensitivity and specificity and critic to validity, the data is very strong, I think, that when a kid screens positive with the PSC, they have a psychosocial problem of some sort.

And we have actually done some work over the past decade to drill down in terms of which types of problems, you know, the subscales show which types of problems.

MEMBER PERSAUD: I have a question. Is there any correlation between the checklist and school readiness? Is there
any information on that?

DR. MURPHY: In terms of tests, academic standardized test scores and stuff?

MEMBER PERSAUD: Yes, predicting bad or poor performance if you have a positive screen and no intervention?

DR. MURPHY: You know, actually, the country of Chile has implemented this on a national scale, so we are getting tens of thousands of cases from them and their educational system is very much like the U.S. system. So they have standardized academic test scores in the fourth grade and they test the kids in the first grade.

And the scores are highly predictive. So we are working on a couple of papers to show that a negative screen in the first grade predicts a poor test performance in the fourth grade.

CO-CHAIR HOMER: Not to be hard-nosed, but do you actually have numbers you could share? So typically on other committees
I have been on, people would submit manuscripts and press and things like that, so we could actually --

DR. MURPHY: We have a manuscript that has been making the rounds of journals being rejected, but we could send you a couple different versions, but, basically, it talks about the association between the PSC score and the standardized test score. So I could email that to the Members of the Committee. It's not quite ready for prime time, but it's readable and rejectable.

MEMBER PARTRIDGE: Charlie, can I --

CO-CHAIR HOMER: Yes, please.

MEMBER PARTRIDGE: -- play a player? I'm putting myself in a user role here.

CO-CHAIR HOMER: Right.

MEMBER PARTRIDGE: I think I understand what has happened in Massachusetts, but I want you to confirm. This was,
obviously, designed as a screening tool, so that it would help the pediatrician or the clinic or whoever pick up the fact that this is a child who seems to have some trouble.

CO-CHAIR HOMER: Right.

MEMBER PARTRIDGE: And what you have discovered by its use, widespread use in Massachusetts, is that, in fact, I, if I were Judge Bigby, who is the Commissioner of Public Health in Massachusetts, saw that there were a lot of these positive scores, somehow that you have been aggregating them so that the information is trickling out from the practice or the clinic, that I have a problem in my community or in my state.

And over time, as I see the referral rate tracking up, it looks like that problem has been eased. Is that how you are proposing we would think of this for an outcome measure?

DR. MURPHY: I think that's a great summary of the leap to, you know, system
use. Heretofore, it has been used again in
the study that Tom was part of, it was -- your
know, are mental health problems increasing in
the United States? So it was used as a part
of some national study.

You know, the regional differences
are there is pediatrician experience and
factors. So exactly those ways. So it has
certainly been used on a smaller scale way.
And now it is being used in a population-based
way to do the things you said.

You know, I haven't spoken about
the outcome measure issue. So we are using it
at Mass General as a pre-post quarterly
assessment. And so, you know, we finally got
it into our own system. And it works, you
know.

CO-CHAIR HOMER: When you say it
works, can you tell me a little more? Like --

DR. MURPHY: I'll try not to get
into much trouble here. Let me talk about
Brad Stein in Los Angeles first.
CO-CHAIR HOMER: Okay.

DR. MURPHY: So it has been used in a number of studies as a pre-post measure of, you know, children who are witnesses of domestic violence and they have a PTSD prevention curriculum in the Los Angeles Public Schools and they pre-test them with the PSC and they post-test them and they use that as a pre-post measure.

So it has certainly been used in half a dozen studies as a pre-post measure in small samples.

At Mass General, we are just using it as it's actually in the flow sheets, every aspect of the flow sheets. We have blood pressure and height and weight and we have a psychosocial area now in the flow sheets of the electronic medical record.

And so the idea is you want to see the PSC scores going down over time. So they do, but we are just -- you know, it's just in the last six months that we have got them in
there and we're using it.

CO-CHAIR HOMER: Tom?

MEMBER McINERNY: Yes. And of course, Massachusetts has what has been going on now for two years, I think, to improve how primary care physicians are able to access mental health specialists to improve mental health care for children.

So if one were doing the PSC scores over time, if this program that was implemented a couple of years ago was working, you should expect to see the number of positive PSC scores decrease, because there is better mental health care. Is that another way of saying this is a way to use this to measure population health?

DR. MURPHY: Yes, it actually is. And actually the data actually show that. We have looked at two years of data, eight quarters of data and the PSC positive rate has gone down slightly from 13 percent to 12 percent or something like that.
You know, there is a sense that
with continued screening and referral, you can
see the rates go down a little bit.

MEMBER McINERNY: And
interestingly, this really could also be a
process measure in that one could say just as
we would expect primary care pediatricians to
be doing developmental screening at certain
ages, a lot of people say, Michael especially,
that primary care pediatricians should be
doing PSCs on a regular basis, maybe at every
well child evaluation and we could measure how
many pediatricians are doing that.

Just like we are trying to get
pediatricians to do BMI percentiles and see if
that is improving over time. But that's only
a process measure. It's not an outcome
measure. But it could be used in sort of both
ways.

CO-CHAIR HOMER: And so just
proceeding along, it sounds like -- are there
further questions about the impact gap
relation to outcomes or that section feels like we have gotten some good information and people seem comfortable with this as an outcome measure?

So now, if we could -- I'm sorry?

DR. WINKLER: We probably need to have the Committee vote on that.

MS. McELVEEN: Yes.

CO-CHAIR HOMER: Because that's a threshold.

DR. WINKLER: Yes, it's a threshold.

CO-CHAIR HOMER: Okay. So how do you vote on this? Do you say simply vote for those who feel it is --

DR. WINKLER: It's yes/no criteria.

CO-CHAIR HOMER: Yes/no important enough to -- important to measure? All those who believe that the PSC indicates something sufficiently important to measure?

DR. WINKLER: 12, 13. Marlene?
Marlene?

MEMBER MILLER: I vote yes.

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

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

CO-CHAIR HOMER: It's like the hand that didn't --

DR. WINKLER: All right. Vote nos?

CO-CHAIR HOMER: Andy, no? One no.

DR. WINKLER: One no, okay, that's fine. Any abstentions? Okay.

CO-CHAIR HOMER: Okay. Let's talk a little, if we can, about, if you could scroll down to, the scientific acceptability component, because that seems a little bit all over the map. Not many voters.

So any comments or concerns about specifications? Is it well-specified measure of reliability, test, re-test and reiterated reliability, validity, which I still didn't really hear a clear answer for you actually on
sort of how well this relates to other
measures of behavioral and mental health. And
how well does it correlate with depression,
ADHD and OCDCL scores, other, you know,
indicators.

DR. MURPHY: If I can have that
fast --

CO-CHAIR HOMER: I'm now beyond my
competence.

DR. MURPHY: So reliability and
validity are not beyond my competence. So
given me that fast ball again, the reliability
and validity have been established in lots of
studies. They are comparable to anything
anybody gets of a brief measure, longer
measures like the Achenbach. Obviously, they
have slightly higher reliability and validity,
but not much.

In terms of -- there was just a
study by Bill Gardner and his associates that
had compared the PSC to a bunch of diagnosis-
specific measures like the CDI and RC Mass and
anxiety, depression, conduct, the ADD and have found that the PSC subscales had similar sensitivity and specificity to those longer and well-accepted kind of gold standard tests.

So again, the PSC is kind of a front end test that can screen for depression, anxiety, attention and conduct problems, you know, with reliability and validity that are comparable to the other accepted standards.

CO-CHAIR HOMER: Okay.

DR. BETHELL: Hi, this is Christy.

CO-CHAIR HOMER: Oh, good.

DR. BETHELL: Sorry to join late. If there are any questions, I just want to make sure people know I was on the line.

CO-CHAIR HOMER: Christy, it's great you are on the line. Christy, we actually had started discussing the National Survey and really deferred. There were so many questions that we felt you were the best person to answer, that we deferred consideration.
We are currently reviewing the PSC, Pediatric Symptom Checklist. And as soon as we are finished with that, we will come back and review. Go back to your measure. So, please, do listen in. But now that we are deep into this, we should finish consideration of PSC and then come back to you.

DR. BETHELL: Great. Just to let you know, I'll be in and out, so this is just to -- you know, I'm not -- I'll be in and out. I will do my best.

CO-CHAIR HOMER: Okay.

MEMBER McINERNY: You know, if you look at 2C.1, that sample, there is some validation description there. And that, to me, looks pretty reasonable, as reasonable as most of these kinds of screen tests can be. And you know, I'm comfortable that the validity is satisfactory.

MEMBER PERSAUD: I would also comment that this score goes down to a pretty low age, age 4. And I think at that age,
there is not or there aren't very many other
validated instruments.

CO-CHAIR HOMER: Yes.

MEMBER PERSAUD: And the PSC has
really, I think, been in the forefront for
that young age group. Actually, in my
practice, we use this as an outcome measure as
well. We have got an integrated mental health
program as a pilot. It's a large state
Medicaid grant in Texas.

And interestingly, we are
screening with a battery of other tests,
MCHAT, mental health tools, PEDs developmental
and then if we find something, it goes over to
a mental health therapist that then does a
number of screens.

This is one, but I'm virtually
certain in the research aspect of this
project, this is being used as one of the
outcome measures. And I think theoretically,
a part of it is if the parent thinks the child
isn't doing well, then that's an outcome.
They are not doing well.

DR. MURPHY: That's a really important point. You know, it's a little bit less sexy, because it's not an MCHAT or it's not something, but, in fact, that single domain of the parent not thinking the kids is doing well is the kind of flag and it actually can be driven down by a good support of interventions of a broad -- you know, of many different scores.

CO-CHAIR HOMER: So there is a category in here that says meaningful differences. So if this were to be used as a performance measure, presumably, you would want to be able to say Program A is different than Program B or State A is different than State B.

It says you hadn't explored that, although you do have, you know, mean and standard deviation measures. Have you really not explored? In the various studies you have done, have you looked at how this can be used
to compare performance across programs or sites or things? I was surprised to see --

DR. MURPHY: You mean as an outcome measure?

CO-CHAIR HOMER: Yes, yes.

DR. MURPHY: You know, you're looking at the PSC Research Team.

CO-CHAIR HOMER: Okay.

DR. MURPHY: I'll give you that. I took a Greyhound bus down here. We don't have drug company funding. So, you know, we do --

CO-CHAIR HOMER: I hope the Bolt bus, you know.

DR. MURPHY: Yes, right.

CO-CHAIR HOMER: It's a little better.

DR. MURPHY: Right. Anyway so, you know, there are whole areas of this that we haven't explored. You know, when Chile starts to use it, we sort of shift our attention to working with them and the
standardized test scores. So some of these population-based things are really new to me and I have very little familiarity with some of the concepts.

CO-CHAIR HOMER: Okay.

MEMBER JENKINS: Wouldn't the proposed use of this quality though in that you are using it to evaluate an intervention? It could be the interventions Donna is talking about or within your clinic.

CO-CHAIR HOMER: Yes, please.

DR. WINKLER: One question. I'm just looking at the information as submitted. The way the numerator is stated, it just describes the survey.

DR. MURPHY: Yes.

DR. WINKLER: So I'm not sure, how do I count that numerator?

DR. MURPHY: How do you score it?

DR. WINKLER: For this measure and then the denominator is, you know, all children, I guess, and I'm assuming so --
DR. MURPHY: Yes, that's --

DR. WINKLER: -- all children in a population, I assume, are eligible. So is this the result, the percentage of children for whom their parents filled out a survey or is it the percent of children for whom -- that had the survey done and it was abnormal or normal or something?

This is what I'm unclear about.

And I don't find the --

DR. MURPHY: I agree.

DR. WINKLER: -- specifications to be particularly precise. I can certainly see where from this tool, using this tool, which seems to be a well-validated at the individual patient level and has a lot of support, but using it to understand more about the quality of care delivered of pre- and post- could be another type of specification, but that isn't what is given to us.

So I'm trying to get a handle on what you are proposing is the exact
specification. What is it we are going to
compare from, you know, about providers? What
information about the quality of care do we
hope to obtain from this measure?

DR. MURPHY: You know, I think
it's a great question. And I think one
problem comes in on two different. I think
you said yourself, you know, the individual
case level is one. On the macro level, one of
the things that is hard to put into words is
that just whether -- I think Tom said this.

Whether a screen was given, you
know, in pediatrics. You know, the reason it
has been pushed nationally is that there is a
requirement to use standardized tools to
screen for psychosocial problems in
pediatrics.

CO-CHAIR HOMER: Sure.

DR. MURPHY: So yes, no. Was the
screening given? What Massachusetts does is
the bill. They have actually tied it to a
billing mechanism, a billing code. You know,
did they -- they gave the screen. They billed for it. And we know what happened.

So at that level, I think, we have done a lot more or we're doing a lot more.

CO-CHAIR HOMER: But you are proposing this as an outcome measure. So as an outcome measure, I mean, as you heard earlier in conversation, we will have opportunity as a Committee to review process measures and this same set could be a very good one.

But you are proposing it also as an outcome measure. So how would -- what would the -- you know, what would that number be?

DR. MURPHY: Well, again, I think as Tom said, I mean, one idea is the PSC positive rate going down.

CO-CHAIR HOMER: So I'm going to be like --

DR. MURPHY: The mean is going down.
CO-CHAIR HOMER: I'm going to be a little obnoxious. For us to approve it, we have to actually have specification. So it has to be different than we could consider. It actually has to be the numerator is either proportion positive, you know, number of children who are positive and positive is above the cutoff of yada, yada or the mean score, you know.

But we actually have to have like written out specifications of numerators and denominators, so that if Colorado wants to apply it, they will apply it in the same way that Massachusetts applies it. So I mean, I think we are just at the limit of our -- we know that mean scores go down.

You know, at Mass General we got in the treatment plan updates that we did. Did the PSC score go down one point in the last quarter? So is that the gold standard number? I don't know, but that's what we are -- so we are just starting to do that.
So we know that mean scores go down. So Marina's was resubmitted as a process. I guess I'm -- my quick take jumping quickly to my global judgment is not quite ready, that is the concept is totally right. We're really excited about the measure, but you haven't presented sufficient specifications for us to make a judgment about whether it is actually a performance measure or not that can be used.

But that's my quick basis, because there aren't specifications. That might be jumping the gun.

MEMBER JENKINS: Well, I was going to say that this is all why I asked my first question.

CO-CHAIR HOMER: Yes.

MEMBER JENKINS: And I guess what I am hearing is that now that we have clarified the question, you may be able to recast this as an outcome measure. Perhaps not for the full endorsement, but that time
limited where you have 12 months to finish up
and fill in the holes of test, retest or
whatever is left.

I'm thinking it is possible that,
Charlie, it's not there, it's just not crafted
that way. Obviously, the use of it as a
process measure is easier and I would totally
suggest we put that forward to Part B of this
discussion.

CO-CHAIR HOMER: Yes.

MEMBER JENKINS: Because as a
process measure, it's easier.

CO-CHAIR HOMER: It's easier, yes.

MS. BOSSLEY: This is Heidi. I
mean, you can put that as a condition with
your recommendation and they can bring back
something and you will look at it again. So
this isn't the last time you could see it. We
could ask for a little bit more recrafting, a
little more rework and bring it back to you.
If again, you don't feel that it is quite
ready, then you can say that or you can say
it's time limited or whatever, all of that.

But it sounds like you would like maybe possibly to entertain looking at this again, so we can ask Dr. Murphy to go back and do a little reworking on it, if you would like.

CO-CHAIR HOMER: Yes, I was just not seeing another meeting as an outcomes meeting.

MS. BOSSLEY: We will give you a call, if you need it.

CO-CHAIR HOMER: Okay.

MS. BOSSLEY: We won't give you a meeting.

CO-CHAIR HOMER: So that's very helpful. So I think actually can I move us almost towards our vote on this or a recommendation?

MS. McELVEEN: That's fine.

CO-CHAIR HOMER: Which is -- and what I think I hear in the recommendation is that, Michael that you have come back, you
I have revised this measure and come back with more detailed specifications for how this could be used as an outcome measure.

I would suggest that rather than approving with a conditional approval, because in part, NQF is sort of trying to move away from these conditional approvals.

MS. BOSSLEY: But I mean, I think what you can do is table it, the discussion for now.

CO-CHAIR HOMER: Yes, exactly.

MS. BOSSLEY: Yes.

CO-CHAIR HOMER: Table it, but, please, come back with more detailed specifications of how this could be used as an outcome measure.

MEMBER FISHER: Could I ask a question?

CO-CHAIR HOMER: Please.

MEMBER FISHER: In the usability -

COURT REPORTER: Can you turn your
mike on, please?

MEMBER FISHER: Oh, sorry. In the usability, it says data has been reported to a court monitor, so are a matter of public record, but not yet published.

CO-CHAIR HOMER: I hear you.

MEMBER FISHER: So you use this data and then you give it to the --

CO-CHAIR HOMER: Well, in Massachusetts there is a legal settlement called the Rosie D case.

MEMBER FISHER: Oh, okay.

CO-CHAIR HOMER: Which the state was sued for providing inadequate mental health to children. And as part of the consent agreement --

MEMBER FISHER: Yes.

CO-CHAIR HOMER: -- this is part of the consent agreement.

MEMBER FISHER: Okay.

CO-CHAIR HOMER: Which is that every pediatrician has to screen. The
agreement was that every pediatrician has to screen for mental health. It turns out that they selected the PSC as one of the instruments.

MEMBER FISHER: Oh, okay.

CO-CHAIR HOMER: So it's under a court order.

MEMBER FISHER: Okay. Thank you.

CO-CHAIR HOMER: But more as a process measure that they screen and that's how much they improved.

MEMBER FISHER: Thank you.

CO-CHAIR HOMER: We're very provincial in Massachusetts. We think everybody does everything like us.

MS. McELVEEN: I just wanted to clarify. Are there any other conditions that you think would be important to be included to find feedback for the developer? I know Charlie specified it pretty clearly, but I just want to make sure everyone --

MEMBER SCHWALENSTOCKER: I think
it would be helpful, and certainly there has
been some discussion around there, if you do
have data about, you know, what you have found
in terms of significant differences pre- and
post-, I think, that would be really helpful.
Recognizing it is early in its use for that.

DR. MURPHY: Clearly, we have to
go to school and get people that know how to
do this and look at our data.

MEMBER ZIMA: Well, I also would
like to think more about this discussion when
we talk about future steps, because this is
kind of the state of the art. And I think
what would be really interesting is, you have
such a heterogeneous symptoms, you know, and
some functioning and it is a little like the
CIS as well.

DR. MURPHY: Yes.

MEMBER ZIMA: You know, and so
what would be very interesting is the Columbia
Impairment Scale, which is a 13 item developed
by Columbia, and it too kind of combines
symptoms and function together.

And so it could be very interesting like with your Chile population, like where you have an adequate sample size that we can maybe begin to tease out, you know, the different domains within this. Because I think eventually we have got to get to the point where we are going to be matching symptoms to recommended treatment. And we are not there yet.

But I think that's something perhaps again we should say best wishes, good luck, good cause and how can we continue this discussion as we think about what the future steps should be around developing quality measures for child mental health.

DR. MURPHY: Yes, that's a great question. I mean, that's exactly the work we are doing now looking at items and clusters and what changes with intervention. Yes.

CO-CHAIR HOMER: So, general agreement that we can table this with strong
encouragement to come back with additional specifications? Terrific. Thank you. Again, wonderful conversation.

So, Christy, are you still on the line? I'm sorry, was that a yes? I couldn't hear. Christy Bethell?

DR. BETHELL: Okay. You know, I got cut off. Actually, believe it or not, it took me about a half hour to get on the call this morning.

CO-CHAIR HOMER: Oh.

DR. BETHELL: I kept getting on and off and I just got off and I'm back on again.

CO-CHAIR HOMER: Okay. So while we have you, and I apologize on behalf of our Committee for hassles you had in joining the call.

DR. BETHELL: Yes.

CO-CHAIR HOMER: We had started a conversation about Measure 34, which is what we are calling Measure 34, the National Survey
of Children with Special Health Care Needs Quality Measures, which included 15 specific quality measures under the broad rubric of the survey.

There were some initial questions, which were just about survey methodology, you know, response mechanism completion rate, you know, response rate, completion rate.

DR. BETHELL: Yes.

CO-CHAIR HOMER: And I just wondered if you could maybe quickly comment on those first?

DR. BETHELL: Yes.

CO-CHAIR HOMER: And --

DR. BETHELL: And just as a caveat, I mean, obviously, with the time that we had, there is only so much you can provide. But also so you know, there are incredibly in depth, hundreds of pages, manual on sampling and data collection and scoring of everything that you see.

So it was a little but unclear
what to provide, so maybe we can, you know, see what we can do now and then just know there is more. So we want to serve it up as it is needed or wanted and in a form that you can -- that you want to have it in, which is, of course, always a challenge.

The National Survey of Children with Special Health Care Needs is a rate and digit style survey feeding off of the sampling frame for the National Immunization Survey. And it is done in a way that yields representative samples at the state and national level.

And then the reading is done to account -- have that be -- all the estimates be representative of children living in each state and the nation and also adjusting for non-response to bias, which is mostly people without telephones, and after being called 20 times, so there is a lot of detailed information about response rate.

But depending on how you score it,
and there are different ways people score response rate. It is anywhere from 58 to 61, I think, percent.

CO-CHAIR HOMER: Which again, I think, in the current year is a pretty high response rate. So --

DR. BETHELL: Yes, but not only that, there is a lot of adjustments made and there has been a lot of analyses done to see whether or not we are really missing groups of people who don't have phones or who have only cell phones. And this is an ongoing discussion with a lot of energy being put in to try and optimize the sample and otherwise adjust on the back end for non-response.

CO-CHAIR HOMER: That's --

DR. BETHELL: There's a lot more to say about that though, so that's a short answer.

CO-CHAIR HOMER: I think that's very helpful. Nancy, you, in particular, raised questions about the sampling issues
response rate. Do you feel like your
responses are sufficiently addressed by that
or do you have any further questions around
sort of just the general survey methodology
and response rate and completion and that?
Because there were sort of broad questions
about that survey, since many people on the
Committee aren't familiar with its use.

Christy, there was also some
discussion and I know you could talk a long
time about this, but I think you can also
present it concisely, just about the screener
and the coherence of that and the issues
involved of having such a diverse set of
indicators for children with special health
care needs. And maybe a brief comment on the
rationale or the experience or how coherent
that set of children ends up being.

DR. BETHELL: Yes. Well, I mean,
if you know, Charlie, the three states on that
page, the definition of children's health
minus the average group, we're trying to
actually identify children who currently have a special health care need, pretty much defined as having an ongoing condition, at least one, most of them have two or more. And that that condition has resulted in above routine need for health service of a type or amount that is required by children generally.

And the screener again, I know, Charlie, you will remember this, started out with about 139 concepts defining consequences and needs that children with current conditions have and then through psychometric testing and medical chart review and administrative data reviews and comparison, basically, identifies the five things that all of them have, all of the children that we want to include have.

So it's not a needs assessment of everything children need. They share a lot in common. They are distinctly different from children who do not meet the screener in every way that we have seen that pattern and we have
a million pieces of data and we always reanalyze it.

Having said that, there is diversity, even if you have a group of children without and they follow along a continuum of need and functioning and other characteristics and consequences now, hereto, no different than any single health condition. And so what we have done is we have created a way to stratify even the screener for how children meet the screener to get some complexity of need and complexity of severity.

And so there are several papers published on that. There is a new paper out by Adam Carle psychometrics independently done. So we have a number of papers that we can present about a variety of issues, whether it is, you know, how the screener holds together or who the kids are that are represented, why they are different from children who don't meet the screener, what about missing cases that we would want to
include and so on.

So if you have more specific questions, I could come right in and tell you. But, yes, there is a range of children represented, but all of them share the experience of having an ongoing condition and experiencing consequences of above routine need or use of services.

CO-CHAIR HOMER: That's very helpful and very concise and I appreciate that, Christy. Bonnie or anyone else with sort of questions about the screener per se and the population that is then reflected in the survey? And again, its importance or relevance.

Okay. I think another set of questions then and really where we were kind of getting a little bollocksed up was the actual quality indicators themselves.

Because one, I guess, one option would have been to submit each of those as separate measures, but you submitted them.
And again I know time was short and I'm not sure what other conversations happened in the background.

    DR. BETHELL: It was really short.

At the time, when there is a lot of other things, I think, I was at your meeting on child measures when they were reviewed. The college had come out a few days before, so it was short.

    But, basically, this is data that your -- these measures that you see before you already have data collected on them. And there is plans to collect that data on a routine basis to provide data at a population level, which I understand is an NQF category or unit of analysis, so they are valuable now for purposes of looking at state and sub-state data. Sub-state meaning sub-groups of children within states.

    So with that frame, it's not like we are screening a measure to obtain any -- this is to collect data. This is data that
exists that could be enforced, if you will, by NQF as measures that are meaningful for some of the categories and unit analysis of measurement that are priority.

So that's one reason to put it together as a group.

Having said that, anybody could take any single piece of it, like the medical home module, obviously collecting the variables that are needed and really just collect the pieces and call it a measure.

Usually when people do a survey, they try to get the biggest things for the buck and being able to get a wide range of information about health, health risks, analytic variables and risk factors along with quality measures at the same time.

So typically, people take a survey and give you 15 different measures. Having said that though, anybody could take it and just collect the medical home module. You know, with all the requisite variables that
are needed to stratify.

But that was the rationale for the group also because we couldn't unbundle them. We had a whole website that takes them one by one and gets the numerator, the denominator and we just submitted that. But I don't think it has been reviewed. But I'm not sure what the format you would want, because it would be tenable for you, you know, to review.

CO-CHAIR HOMER: We are not sure either, but so we are just working it out today.

DR. BETHELL: But we have a lot, and then I think that they do vary, the measures that are within there, in terms of where they come from. Obviously, the screener was validated and adopted into the survey before the survey was placed. The medical home measure was a specific year long measurement development and testing for more than a year, but formally a year.

Some of the other ones are items...
that come from other surveys. Some of them
were developed and tested cognitively and then
subsequently people have published on most of
the measures in a way that has been through
pretty extensive purity process where there
just had to be demonstration of IMs are all
that they say they are. And there is a number
of different ways to conduct the validity
question as well.

CO-CHAIR HOMER: Okay. Kathy?

MEMBER JENKINS: Could I just ask
my same question that I asked the last measure
developer related to this list in terms of the
use of this information as an outcome measure
as opposed to structural process? Because I'm
not going to what Dr. McInerny said before and
I agree with him. And to me, the list is
variable in that regard.

DR. BETHELL: Well, it wasn't
clear to me actually with the call to
measures. I agree with you. What the -- like

with the medical home, what if -- it just
wasn't clear to me what that would be categorized as, if we were generous and included things.

CO-CHAIR HOMER: In other words, you think this is a mixture of process and outcome measures?

MEMBER JENKINS: As an example, the one that says proportion who are screened early and continuously. I assume that since you have put it forward, you are regarding variation or cross-set as an outcome measure?

DR. BETHELL: You know, again, the call for measures didn't make it clear to me where you were. You know, there is a continuum of what people think of as outcomes. So if you are speaking health outcomes, then there is a subset within there. And it's very tricky to get at health outcomes, but there are some that are in there like how much the child is affected.

I don't have the list in front of me, so if you could maybe call one out in
specific, I could address that.

MEMBER JENKINS: I guess my general question is, have you developed any of the evidence that the individual items are linked to child health outcomes or predictive of child health outcomes? In a formal way, as opposed to just on the face of it.

DR. BETHELL: Right. Well, keep in mind that the National Survey is, and this would be true for state level, a cross-sectional survey. And so the validation is really internal to the sampling frame that is there.

And, yes, there are all these associations you would expect to show up that children with certain levels of system performance, if you will, whether it is inadequate insurance or having a medical home, vary as expected on the other more outcomes-oriented frames, adjusting for all other things that you might want to adjust for that also might contribute to variations in those
outcomes.

So that kind of data does exist. And then there are separate studies where people have used pieces of the survey in independent studies with independent data collection where some of that also comes out. So I think all of that together would be a task, and I think the question was if there is enough interest to justify moving forward with that level of work.

CO-CHAIR HOMER: I think actually we may need to go one-by-one to actually answer some of those questions, if that's not too painful, I mean.

DR. BETHELL: Yes, it's not too painful, but it's an extensive process and that's why I was not clear how we were going to really proceed with this.

CO-CHAIR HOMER: No, but I was even thinking as a Committee task right now. I mean, I could say, for example, your first-- I appreciate you don't have the list in front
of you.

So the first one was the effect of a child's conditions on their daily life. So presumably, that's an outcome measure. That is, there is some indicator of, again, I don't know what the response categories are and what that actually means to say, affect on their daily life, but I'm sure that's something like impaired or not impaired or interferes or doesn't interfere or something along those lines?

DR. BETHELL: You know, this may sound really wild, but because the Committee is needing this information, it actually is all up on our website. Like if you went to the website and clicked on that list over there, there is a box that pops up that is numerator/denominator, if you want to see the exact questions that are in it, you just click and they come up.

And I am not sure how to be more efficient than that without giving you a
binder that is like 3 inches thick. You know what I mean?

CO-CHAIR HOMER: Yes.

DR. BETHELL: So that's just an idea.

CO-CHAIR HOMER: So I can get that up for our team. It's cshcndata.org, right?

DR. BETHELL: Yes. And so you go to the actual measures. There is a detailed box at the end that you click on that pops up a pop-up box and then in that there is additional things that you can click on.

And we have not summarized all the articles that have been published on these different measures that are showing. And we haven't -- I wasn't clear what the context that you most want to see them for, purposes of, because you have the population health area now. It seems to me that they are most relevant to that, where you are not necessarily trying to pin down the association with the delivery system each child is
associated with, but rather looking at population health.

So I think that that's the easiest context in which to endorse these measures, if you will. Stratification can occur by type of insurance, by all kinds of other variables, but it was not going to link it up to a health plan or something like that, so that's not the model that would be appropriate to view these measures through, at this time, unless the survey will recommend it to be applied, as a unit of analysis, you know, it's reasonable, but would be a different specification altogether in terms of handling and risk adjustment.

CO-CHAIR HOMER: So we are actually getting your survey up on the screen here as we go, and so we should presumably click on the 2005/2006 National Survey, right, of CSHCN?

DR. BETHELL: Yes. And while you are doing that, Charlie --
CO-CHAIR HOMER:  Yes?

DR. BETHELL:  -- I would just say from a context point of view, all of the survey -- the survey is designed with the close involvement of a technical expert panel sponsored by the Maternal and Child Health Bureau.

CO-CHAIR HOMER:  Okay.

DR. BETHELL:  And various tests along the way either through our organization or another organization, often the CDC or the National Center for Health Statistics. So before items and measures are on the pinnacle at all, they go through that process.

Not unlike a group like you all, I mean, in terms of the concept of a technical expert panel. So if that gives you any comfort, I want to say you should do that.

CO-CHAIR HOMER:  We are having a little trouble getting very quickly to your numerator/denominator questions. Can you quickly --
DR. BETHELL: Yes. Well, if you go to the measure, I can presume that you know how to do that. We're redesigning the site right now to get a very simple way, but if you go to the core outcomes, key indicators and core outcomes and the chartbook measures?

CO-CHAIR HOMER: Yes.

DR. BETHELL: Yes. And then there should be a category that you will see, consistently in affecting children's life, for example. You should find that measure on the list.

CO-CHAIR HOMER: No, I'm sorry, I'm going in parallel to the screen which is not a good thing to be doing, so I should be --

DR. BETHELL: Okay. I wish I was there to help you. Well, anyway, at the end of the -- you find the measure and then at the very end of it, there is a little, I think it is a globe in parenthesis, it's the word details. And if you click on that, the pop-up
box comes up that basically walks you through
the numerator and the denominator.

And keeping in mind that the
denominator is all children for whom this
question was asked at a population basis. And
it is representative of the population of each
state. That's the question actually that is
about all children who qualify as having
special health care needs.

So there isn't any exclusion
criteria for that one. Care coordination,
there are exclusion criteria, for example. So
that would be -- that is made as clear as
possible in a summary way in that pop-up box.
And then if you want to see the actual items
that are asked, they are highlighted and you
click on them and then it comes up.

But this is one of the simplest
ways to be able to figure out how to run
people without into it literally providing a
hard copy document that is -- that's also
possible though.
CO-CHAIR HOMER: But I just don't see -- while the information is all here and wonderful, it's probably not an efficient use of the Committee's time for me to be working through it. I don't know, Committee, what do you think here?

DR. BETHELL: We talked with Tom about this and I think that there is a lot here and it wasn't clear to me exactly how you would want it. And also the time is not sufficient or, you know, I wouldn't want to spend so much time putting it in a format if that wasn't the one you wanted. And so maybe this discussion can be, is there interest in looking at the National Survey, the data produced for the measures they have produced at a population health level.

And if so, what would you want, you know, or how would you want to know it?

CO-CHAIR HOMER: Kathy?

MEMBER JENKINS: It's just going to be a recurring thing for me. I think that
the survey itself is, you know, wonderfully
developed and rich with information.

The question at hand is about
child health outcome measures and they have to
be well-specified and that's what we need to
evaluate. We just need to see the information
in sufficient detail that we can do that.

I would be willing to allow this
issue, definitional issue, about when
something that may look to others like a
process or structural measure can, in fact, be
construed as an outcome measure, but I would
like to hear the steward articulate the
rationale for that, so that we could all be
sure that we understand that.

DR. BETHELL: Well, you know, I
actually would want to hear more from your
guys' angle, because it wasn't clear in the
call for measures where you went down that
concept. So that's why there are some things
in there that I would consider to be -- you
know, it depends on what outcome you are
talking about: intermediate outcome, long term outcome, or system outcome, like having, you know, experience with the medical home, some people call that an outcome, some people would call that a process. So at least it would be great for us to hear about that.

But again, if you are doing to do a survey or if the survey data already exists that you want to stick in, the CSHCN survey is completing good administration, so that you have nine tenths right now, it's not like you go out and just collect data on one piece of it. It's creates a picture of performance for a population of children across process and outcomes and so that's one of the reasons for presenting it as a holistic survey.

CO-CHAIR HOMER: Right. So again, Christy, we had discussion earlier on the analogy to CAHPS, so, you know, CAHPS is approved as a tool. And there are a variety of measures that came out of that. And again, I think this Committee is comfortable with the
validity of this as, you know, a high quality survey.

I think the question that we are still wrestling with, and again, the question we are still wrestling with, is the utility validity -- the validity and utility of some of the specific measures that are derived from this.

And then secondarily, whether some of these are best considered processes or outcomes. What I think is, we can quickly go through the list that you gave and figure out which ones are no-brainer outcomes. Like, you know, missing school or impact on function and things like that.

And the staff, maybe during lunch, maybe during some other time, we, can pull the specifications or maybe we will have to have a conference call or put some of this off until tomorrow, we can pull the specifications from that from the survey from your website pretty easily, we just haven't done that yet.
So I think that's one thing that we need to do. We can go through this list and, like I said, some of them are clearly outcome measures. There are some that are on the fence, like having a medical home.

And again, I think those are difficult. I'm not sure how much usefulness it is for us to really spend a lot of time.

DR. WINKLER: Charlie, can I just step in?

CO-CHAIR HOMER: Yes.

DR. WINKLER: Christy, it's Reva Winkler from NQF. Just in other aspects of the outcomes project, we have looked at other measures that are composite measures that have been a mix of process and outcome measures, because it had an element of the outcome measure, it was included.

So I don't know that we need to be quite so black and white. I think the issue around this is the question of this measure, as defined and submitted, gives us 15 results.
And so I would consider it a multi-part measure, if you will.

There is no summary that would turn it into a single composite, so it's a multi-part measure. And I think the question for the Committee is is this a useful, meet all the criteria, measure, given it has 15 parts to it? And look at it from that perspective.

The fact that it is a mixture of process and outcome measures, I don't think you need to spend a whole lot of time on.

CO-CHAIR HOMER: Okay.

DR. BETHELL: Yes, I would love to have the opportunity to come back again, too, because there is a composite version of the core outcome for CSHCN, but, you know, how many of the core outcome children have. And it's a system outcome performance measure in that regard.

It's really, you know, very minimal. The bar is very low in terms of
these measures. These are, if anything,
getting positive views of how things are going
just by nature of the fact that they are part
of the report and they can't be specified, you
know, in really, really detailed ways.

But when you have a composite,
which is proportion of children meeting all
five system criteria or 3Q-01, and that is
very aligned with issues like having adequate
insurance or other process measures and so on
and so forth.

So there are some ways to score
them in a composite-like way, but I didn't put
that forward because of time mostly and also
because I wasn't sure what would be of
interest. But that is possible to do even
more than what you are seeing and has been
done.

CO-CHAIR HOMER: I see no way for
us to not, basically, have staff and maybe
even some Committee Members working with staff
come back to you and try to get -- I know you
have the information and I know a lot of it is
on the website. I think we are going to have
to sort of boil this out, synthesize it, and
come back.

DR. BETHELL: Yes.

CO-CHAIR HOMER: I can't think of
any other way around it.

DR. BETHELL: Yes. I thought that
would happen. I mean, that's sort of -- it
was sort of a stretch, you know, to get it to
you in the level of detail. I mean, it was a
lot of unexpected, you know, and quick
turnaround and we did our best. So with your
conversation and feedback, we should be able
to go to the next step.

CO-CHAIR HOMER: This is two in a
row that I'm doing that on, so this may end up
being unsatisfying. So what is --

DR. BETHELL: Yes.

CO-CHAIR HOMER: -- the
Committee's --

DR. BETHELL: Well, that might be
Reflective of the, you know, quickness and things. And it may just be a natural part of working out what you need.

DR. WINKLER: Charlie, as unsatisfying as it might be, if you are not in a position right now to recommend the measure, then Plan B is a definite alternative.

CO-CHAIR HOMER: Because I mean, I think, my sense is actually the work group that reviewed this did not feel comfortable enough with what they saw to go forward with it, and I think that's more because the supporting information simply isn't there and unfamiliarity with some of the details of the measure.

So I would, rather than have sort of an up or down vote on kind of what we have seen now, we do spend the time and go through that and bring it back.

MEMBER PERSAUD: And can I ask in the sort of the way we're looking at the data that we do get to look at the composite
DR. BETHELL: Yes.

CO-CHAIR HOMER: Sure.

MEMBER PERSAUD: The details of that, I would really like to see that.

CO-CHAIR HOMER: Okay.

DR. BETHELL: Great.

MEMBER ZIMA: I would have to say that these last two we put in promising practices, you know.

CO-CHAIR HOMER: With the difference between the last one is on this one, there are specifications, we just haven't teased them out. So they exist. This has been used for comparative analysis before. There is actually a website they even go to compare Alaska to Montana, if you want on sort of any one of these metrics and whether there are significant changes over time, et cetera.

So I think the difference between this one and the last one is the last group, great concept is being used for a variety of
things, but really hasn't been specified in
frames that we could use. This one has been
specified, but hasn't been presented to us in
a way that we can synthesize.

MEMBER PARTRIDGE: I have just a
quick question for Marina. This is Lee,
Christy. You have got a measure with 15 parts
is what we are talking about here, I think
that was how you described it.

As we consider some of the 15
parts and will we end up voting? No. I'm
trying to figure out if we say we like this,
but we really don't like Question 714 and 3,
what have we done?

DR. WINKLER: This is Reva,
Christy. Essentially, since it was submitted
as a multi-part measure, it's an all or none
from that perspective. However, it could be
conditional with removing 6, 12, 13 or
whatever, but I don't know if that's something
that is, you know, amenable.

So it would be part of this
discussion back and forth. But given it was submitted as a multi-part measure, that's what you are looking at.

MEMBER PARTRIDGE: Right.

CO-CHAIR HOMER: Tom?

MEMBER McINERNY: Tom McInerny.

You know, really, when you look at these measures, there may not be any correlation between the measures at all. And my argument would be we should make this 15 different measures, because someone could have a medical home and a usual source of care and insurance, but they may not have family-centered care or they may not have easy access because, you know, the practice is overwhelmed because they do such a good job.

I don't know. But so really the problem is you're going to, as you look at these, you're going to see some are going to be high, some are going to be low, some are going to be in between. And then I don't know how you put it all together. In my mind, it
might be better just to say make it clean,
make it 15 different measures and just look at
each one.

MS. McELVEEN: The other thing to
keep in mind is they also submitted another
large survey measure that is actually
comprised of 22 individual measures. And,
Christy, you can correct me if I'm wrong, but
from what I have gathered is that some of
those smaller individual measures do overlap
somewhat between the two surveys.

And I think the one on care
coordination may be a good example of that
overlap. So once we get to those other
measures, which are all falling under Group 3,
if I'm not mistaken, once the Committee kind
of looks through each of those individual
measures, you may find your ideas and outcomes
or decisions may be a little different
depending on that.

And I also think that it is
important that we look at this composite
measure that was not submitted, obviously, for
the group, but it sounds like that would be
valuable for the group to review and possibly
as a component of the larger set of measures.

CO-CHAIR HOMER: Kathy?

MEMBER JENKINS: Maybe it would be
useful to try to walk through the Committee
process on those item measures because, in a
sense, they have presented some of them from
that framework, right? I think they have for
whatever reason chosen those as probable
outcome measures. And we may find ourselves
able to approve those and it may also be
useful to the group to figure out how to
present the broader group in a way that would
be helpful.

CO-CHAIR HOMER: So are you
suggesting that we right now start moving
through some of the individual measures within
those 15?

MEMBER JENKINS: The ones they
submitted, yes.
CO-CHAIR HOMER: No?

MEMBER JENKINS: The ones that were submitted.

CO-CHAIR HOMER: The separate ones?

MEMBER JENKINS: Yes.

CO-CHAIR HOMER: Okay, good.

MEMBER JENKINS: Yes.

MS. McELVEEN: In other words, the recommendation is tabled for this one.

CO-CHAIR HOMER: Okay.

MEMBER JENKINS: Right.

CO-CHAIR HOMER: Okay. So again, as a little bit with the previous one, the motion on the table, basically, is to table the broad consideration of, actually, both 33 and 34, although we actually haven't reviewed 33 in detail yet.

For us, for staff to work with Christy to come up with a clear presentation with additional background data for that and whether we -- clearly, the sense of the group
is we want to see the full composite measure.

I think we want some reflection for decision, again, between the steward and the staff as to whether it comes back as separate items or whether it comes back as a multi-part item.

I think we are not making that judgment yet as a Committee. So, okay.

And then the next idea on the table is moving to some of the individual items.

MS. McELVEEN: Would 35 actually be the next one?

CO-CHAIR HOMER: Okay. So do you want to put up the summary of 35? 35 is Children who take medication for ADHD, emotional or behavioral issues. Anyone who was on that work group want to describe either their impressions or walk us through the assembled vote of the Committee, which is sitting up on the screen?

MEMBER SCHWALENSTOCKER: Charlie,

I need to actually pull up the thing on my
computer, because I can't see the screen, but my initial take on this measure was, it seemed more like a process measure to me than an outcome measure. So with that brief comment, I will try to find my document here.

MEMBER ZIMA: Oh, we were a small sample size.

MEMBER SCHWALENSTOCKER: Yes.

MEMBER ZIMA: And psychiatry gets even smaller.

CO-CHAIR HOMER: Yes.

MEMBER ZIMA: But I think that my initial impression was not -- was lukewarm only because I looked again at the numerator details. And what I struggled with most was that medication is often indicated for ADHD, but it's not necessarily indicated for this other broad group, other emotional or behavioral issues.

And so I think again it kind of highlights taking this issue and putting it on sort of the next step, future steps, because
there is variation and a level of evidence for treatment for particular psychiatric disorders.

And I think we are getting caught up in sort of a dynamic where initially we were describing mental health problems, psychosocial problems, you know, mental health problems, behavioral, emotional or behavioral, serious emotional behavioral disorders, but there is now a little bit of a trickling where maybe we can better specify diagnosis and link that to a particular recommended treatment.

We are not there, but again when you lump this together, for me, it makes it very problematic to make any sort of assessment of whether that child got good care.

MEMBER FISHER: Don't you think -- you said about the controversy is that looking at the age group, 2 to 17, you started talking about mental health problems and things. You really are going to get into off-label use of
medications, and it is hard to second guess.

And so, I mean, that really brings a controversy when people are trying to deal with us now what do you do with the children, say, at three that I know some that really needed medications, but you don't really want to put them in this group.

They may be getting good care, but that's just like you said, that is not where you want to go.

MEMBER PERSAUD: Yes, I mean, I'm really worried about having the 2 to 3 or 4 year-olds mixed up in this group, because I think the literature is unclear about whether you should be really calling it ADD. And I think you are definitely at off-label use of meds. And I don't agree that medications for other emotional disorders should be in this group.

This group needs to be clean and I think the most latest discussions in the ICD-9, 10, ICD-10 about the elimination of bipolar
disorder that became a big group, that is another group that is going to be mixed up in here, that people are using medications on where that practice is really being looked at right now as to whether that is good practice.

MEMBER ZIMA: There is also one more moving target, I think, when we think about child mental health. And again, this is probably for tomorrow's discussion, and that is the changes in the DSM-V.

So you know, this debate about the age, well, they have thrown out the age of onset for the ADHD diagnosis. But again, I don't think the evidence is there for the younger child.

And so then if you are going to be talking about the controversy of bipolar disorder, then that's going to also again, I think, for future steps and probably for many years, start thinking about, well, how in the world did they get this dysregulation syndrome diagnosis that is being proposed?
So just --

MEMBER FISHER: I think there is also, when you bring that up, if you have a really clean -- and we are talking about ADHD, then that's an opportunity to look at to see about quality care in those kids, because there is some evidence that kids are being over-medicated.

And so, you know, you're right. We need to look at one thing, make it really clean, define it, so we can do some quality improvement.

MEMBER RAO: I just want to echo that a little bit. I mean, I think this is a measure that is very prone to abuse. I mean, there is lots of children with ADHD who probably don't need to be on medicine. So if this measure goes out and says well, 8 percent of your kids are treated and 92 percent are not, is that good or bad is really going to be difficult to say, at this point.

MEMBER ZIMA: You know, it's
interesting, because the data might suggest
sometimes it is over-medicated if you look at
Medicaid claims data, but when you look at
actual treatment adherence, it's incredibly
low.

And so, I think, again this goes
to sort of tomorrow's discussion, because
there has to be much more emphasis on the
family-centeredness and the parent preference
for treatment around mental health problems
and how that also changes over time for that
parent and that child.

And so I think, you know, on the
table again for maybe future steps is, how do
we also integrate parent preference in
treatment when thinking about scoring the
indicator?

CO-CHAIR HOMER: So I think from a
threshold perspective, I mean, no one could
argue that the use of psychotropic drugs in
children is an important issue and there are
many controversial elements to it.
But this measure, that is the proportion of children with some form of behavioral problem who are on medication, one could really argue whether this meets threshold criteria for importance, because the meaning of the measure is so unclear.

So I would actually propose a quick threshold vote on this on the importance criteria. And, Reva, would you call it, please? Let me know if you think I'm misinterpreting importance, but at least from my perspective, I'm having a hard time lining up this measure with any concerns people might have, so I would like to say it doesn't meet the criteria for importance and we could not even get into the issues of feasibility and usability and specifications and all that.

CO-CHAIR WEISS: Maybe this is just a different way to ask the same question, but as a non-clinician, my question is if we know the answer, what do we know? How do we deal with it? I mean, maybe it's patient
adherence. So I guess I would second the comments that Charlie has made about maybe this doesn't meet the most fundamental of all of our thresholds.

MEMBER JENKINS: I just wondered if the measure developer wanted to respond before we voted, in case we missed something?

CO-CHAIR HOMER: Good. Christy, are you there? Is the phone still there?

Marlene, are you still there?

MEMBER MILLER: I'm still here.

CO-CHAIR HOMER: Oh, good. Okay. Just wanted to make sure the phone was still working.

DR. WINKLER: Christy, said she would be in and out.

MEMBER JENKINS: Yes.

CO-CHAIR HOMER: So, okay.

MEMBER JENKINS: It doesn't matter.

CO-CHAIR HOMER: So anyhow, I would propose that we have a vote on
importance. All those who would vote that
this is sufficiently -- and I'll do it on the
positive this way. Let's say this is
sufficiently important to go forward and that
it meets the threshold criteria, raise your
hand. Okay.

DR. WINKLER: Marlene?

MEMBER MILLER: Just to clarify,
does this may mean that more information will
be forthcoming then on the stuff we have
talked about?

CO-CHAIR HOMER: This one, no. We
are saying if this is voted no --

DR. WINKLER: That's it.

CO-CHAIR HOMER: -- then we don't
want to know any more about this question, you
know, about this particular item.

MEMBER MILLER: So if we say yes,
then more information will come?

CO-CHAIR HOMER: Yes, then we have
to have a broader conversation about this
measure.
MEMBER MILLER: All right. Yes, then I vote yes.

DR. WINKLER: Okay. That's one.

CO-CHAIR HOMER: Okay. All those who vote that no, this does not meet the importance threshold for further consideration? Allan, are you voting?

MEMBER LIEBERTHAL: I'm having some struggle here.

CO-CHAIR HOMER: Okay.

DR. WINKLER: Are you abstaining, Allan?

MEMBER LIEBERTHAL: I'm abstaining.

CO-CHAIR HOMER: Okay. All right.

MEMBER LIEBERTHAL: I just lost all my reviewing reports.

CO-CHAIR HOMER: Okay. So one in favor, 13 against, 1 abstained.

DR. WINKLER: One abstained.

CO-CHAIR HOMER: Okay. So it doesn't meet. Ellen?
MEMBER SCHWALENSTOCKER: Charlie,

I'm sorry, not to put too fine a point on it. It's not that I would say I don't want to move it forward because it's not important. I think it's an important issue, but I think -- so it's not right, in my mind, to say it's not important. It just doesn't meet our other criteria for what we are trying to measure. Is that --

CO-CHAIR HOMER: Right. I knew I was stretching the --

MEMBER PERSAUD: I think it is important because of the way it is --

MEMBER SCHWALENSTOCKER: Yes.

MEMBER PERSAUD: Okay.

MEMBER SCHWALENSTOCKER: The way it's written.

MEMBER PERSAUD: I mean, every issue is important. This measure isn't constructive in a way that it meets the criteria.

So for the record, I think the way
this measure is constructed, that's why it is 
not important, because the construction 
doesn't meet importance, not that the topic 
isn't important. And I don't think that's 
what our charge is.

DR. WINKLER: Also just to 
reassure everyone, NQF has already endorsed 
several measures, process measures, around 
management of children with ADHD and 
appropriate follow-up care for those on 
medication. And so it's not as if the topic 
doesn't have some measures associated with it 
already.

CO-CHAIR HOMER: Okay. Let's move 
on. Hey, we got something done. That's good. 
How are we doing for time?

MS. McELVEEN: Okay. So we are 
about 12:20. I think it would be worth going 
through another measure that, again, was 
submitted by CAHMI, an individual measure. 
And after that, we can go ahead and probably 
break for lunch, but if we could get through
that last bit of measure, we would have at least completed what we said we were going to complete before lunch. So that's good.

So this is Measure 37 and this is a measure, Children Living with Illness: The Effects of Condition on Daily Life. And this measures the extent to which conditions of children with special health care needs results in limitations of their daily activities, despite health care services received.

So again, we will open this up to the group for discussion looking at, of course, importance and scope as kind of the first items on there.

CO-CHAIR HOMER: So again, could we hear from the --

MEMBER ZIMA: I guess my biggest concern was I thought maybe this was more of a severity indicator and that depending on the type of -- depending on the care, some children would get better and some people
would remain or maintain a certain level of functioning.

And it didn't seem like we could really -- I could really interpret the meaning of this indicator the way it was written.

MEMBER JENKINS: Are you looking for risk adjustment?

MEMBER ZIMA: No. I was thinking more in terms of, again, more clinically. And maybe this is a problem. But some disorders don't get better and will always have a certain limitation in functioning. And even under good care, for example, like an autistic child, you are going to maintain a certain level of functioning.

And whereas a striking example would be an ADHD kid with proper medication, behavioral treatment and special ed, they might get -- their functioning might improve dramatically. So I wouldn't be able to tease that out.

MEMBER FISHER: Also, to add to
that, there are kids with special health care needs that are severe who are going to get worse. And so the idea is that you have to support them as they get worse, but that's even harder to evaluate. They need good care, but they are going to deteriorate.

CO-CHAIR HOMER: All that being -- well, okay. Maybe to be more formal, should we first wrestle with the importance issue? Do you think this is an important topic? That is, the problem is prevalent enough, there is likely to be some variability across jurisdictions or systems. There may be disparities. This may reflect disparities in care. Again, those are the criteria for importance.

Again, first there is the threshold for then do we go on to some of the other aspects?

MEMBER PARTRIDGE: I don't have the specs in front of me. Can we answer some of those questions from the materials
submitted?

CO-CHAIR HOMER: What it says is,

38.5 percent of children with special health care needs, health conditions have a moderate effect on their daily activities.

MEMBER PARTRIDGE: Does that surprise you?

CO-CHAIR HOMER: No.

MEMBER PARTRIDGE: Okay.

CO-CHAIR HOMER: But there is an indication that this is --

MEMBER PARTRIDGE: Right.

CO-CHAIR HOMER: -- a big deal as opposed to a little deal.

MEMBER PARTRIDGE: Correct. So then I think I would want to know, given that, what more information do we have?

CO-CHAIR HOMER: The range across states is from 18 percent in Iowa to 30 percent in Oregon. Now, so there is variability across states.

MEMBER PARTRIDGE: And we don't
know how that correlates with the conditions we are talking about?

CO-CHAIR HOMER: Well, we do know that poor children have conditions that consistently affect their daily lives more than twice as often, 35 to 15 percent. Kids with a medical home are twice as likely to have health conditions that consistent, so that actually -- kids without a medical home are twice as likely to have a health condition that consistently affects their lives, 30 to 15 percent. So there is some.

MEMBER PARTRIDGE: Some.

CO-CHAIR HOMER: If you do have a medical home --

MEMBER PARTRIDGE: Right.

CO-CHAIR HOMER: -- you are half as likely to have a health condition.

MEMBER PARTRIDGE: Right. So you get a -- you can drill down, in other words, and look at different dimensions based on the answers to these questions.
CO-CHAIR HOMER: Yes.

MEMBER LIEBERTHAL: Unfortunately, my USB port seems to have died or I'm having trouble, so I'm not able to look at the specifications very well. But the way I read just the summary of the question, this refers to a population of children who are getting services and are still having their -- their lives are still affected. Am I reading it correctly or not?

Because if there -- because if I'm reading it correctly, what you are dealing with is the base line of their special health care need and, therefore, all you are identifying is the floor of what is possible.

Now, if I'm not reading it correctly --

CO-CHAIR HOMER: I don't think --

MEMBER LIEBERTHAL: -- then I don't know what the wording is.

CO-CHAIR HOMER: I don't think --

MEMBER PERSAUD: The denominator
1. is all children ages 0 to 17 who have special
2. health care needs.

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

MEMBER PERSAUD: If you actually scroll down to the specs, scroll down to 2A or whatever.

MEMBER JENKINS: There you go.

CO-CHAIR HOMER: Do you have any--

MEMBER PERSAUD: I'm trying to think about the answer to Bonnie's question about severity and whether -- and I don't know how this questionnaire is constructed, but just trying to think about if the questionnaire is constructed consistent with what -- with good care, someone with disabilities might have, if it's constructed around -- I mean, I'm thinking except for maybe ventilated assisted patients, even those that are near vegetative with tracheostomy still can be transported to school and spend the day in school and be cared for.

Would that be -- you know, if they can go to school and be cared for without
multiple interventions, would that be regarded as the acceptable level of daily activity? And if that's impaired, it is at issue. It's I think just a matter of whether the question is asked appropriate to the best possible outcome from someone with that level of disability.

CO-CHAIR HOMER: I was just trying to put the actual question up on the screen.

MEMBER JENKINS: Yes, I was just going to say that my take on this is that what we are struggling with is whether or not this is all crafted scientifically, so that we could understand variation as a quality measure and that those are really kind of part of the scientific issue here.

But that it is meeting my criteria for importance as crafted, as it is even meeting my criteria as an outcome measure.

CO-CHAIR HOMER: Great.

MEMBER JENKINS: And we are hearing about gaps. You know, it may fall
down when we talk about the scientific issues in terms of Donna's issue around is the question crafted in a way that all people would answer it and Bonnie's around what I would regard as risk adjustment and then the trajectory of disease and what is preventable.

Those are different issues to me, but I think my answer to you, Charlie, is yes, it passes the first threshold for getting into that broader discussion.

CO-CHAIR HOMER: Yes, right. So why don't I call a vote on whether people think this is sufficiently important to proceed with the conversation, so that we can go on. So we will have a vote on that.

All who vote yes, this meets the threshold criteria for importance, so that we can then go into the more detailed issues around validity and feasibility, usability, et cetera. So all those who vote yes?

DR. WINKLER: Marlene?

MEMBER MILLER: Yes.
DR. WINKLER: Thank you.

MS. McELVEEN: That's 14 yeses,

and that was everybody.

CO-CHAIR HOMER: Okay. Good. Let me just read the items. Let me just read the items just because I'm so proud of having found it.

It says during the past 12 months,

how often have blank medical behavioral or other health conditions, emotional development or whatever it is, how often has Suzie's condition affected his or her ability to do things other children their age does? That's sort of the question.

Okay. So it's a very broad question.

CO-CHAIR WEISS: So affected could be positive or negative. Either made it possible or inhibited it.

CO-CHAIR HOMER: Yes, at least that's Question CQ, whatever it is, 2. And it also says Question 3 is supposed to be in
here, right? So anyhow, C3Q, Section 3, Question 2, that was the item. I can try to find what Question 3 is as well. But at least you get some sense. Maybe that helped, maybe it didn't, but now you know what the question is that we are dealing with.

CO-CHAIR WEISS: We know the population.

CO-CHAIR HOMER: So why don't we then continue? We have talked about it meets the importance criteria. What are the next set of criteria that we should be considering?

Scientifically acceptable. So comments from the reviewers as to its level of scientific acceptability?

MEMBER PERSAUD: So I do see in here that it specifically says it is not risk adjusted and so when you gave that opening question and it's not risk adjusted, I think it doesn't answer Bonnie and my concern about appropriateness and being able to assess the results, because they don't match the
expectations, I think, of the need,
especially, you know, their function or what
their true function could be.

MEMBER DOCHERTY: Isn't it the
validity question? Is it really measuring
their ability to improve their daily living as
compared to other children their age or
compared to children with similar conditions?

MEMBER PERSAUD: Well, I think
that's really --

CO-CHAIR HOMER: But if you are --
the next item, by the way, and I'm not quite
sure how different it is, does ask is medical
behavior or other health condition affect his
or her ability to do things a great deal, some
or very little? So I guess that's the -- the
first one is does it affect it and then the
next question is does it affect it a great
deal, you know, somewhat or very little?

That's sort of the severity of
impact on function or on daily life.

Let's go back to Kathy's earlier
observations though. If this is applied at a population level, so if you are comparing Alaska and Indiana or Ohio and Oregon, which is, I guess, where they were comparing, would you expect that at a large enough population levels that big a difference in distribution of health and disease that it would threaten its validity?

I mean, I guess if the sickest patients in the country moved to Oregon or, you know, Des Moines or whatever, it might, but otherwise, it's probably hard to imagine.

MEMBER FISHER: I think -- oh, I'm sorry.

CO-CHAIR HOMER: I'm sorry.

Nancy, go ahead.

MEMBER FISHER: Go ahead. You were first.

CO-CHAIR HOMER: Tom?

MEMBER McINERNY: Well, I think there is some evidence that certain states have a richer set of benefits for patients who
have special health care needs. And so patients will preferentially gravitate to those states. And that could certainly skew your results.

CO-CHAIR HOMER: Okay.

MEMBER FISHER: I was going to say the same thing. And to add to it, you have to look at whether --

CO-CHAIR HOMER: Turn your mic on, please.

MEMBER FISHER: -- you are on the east coast or the west coast. And the reason why I say that is about gravitation, because people forget Wyoming only has a half a million people.

CO-CHAIR HOMER: Right.

MEMBER FISHER: And then Montana, which is huge, has a million. So the resources there are less and those people will move to where the resources are.

So let me give you an example. You can move out to Seattle and there are a
lot of people there with Huntington's Disease
that have moved from other places because of
the expert that is there, a neurologist who is
also a geneticist, so you get all of these
people that move in.

So you know, it depends on what
portion of the country and how big your state
is and how populated.

MEMBER PARTRIDGE: Charlie, I
think I would also add there will be
differences in the incidents of certain
conditions based on the population of that
state. In the District of Columbia I had a
fairly significant rate of sickle-cell.

CO-CHAIR HOMER: Yes.

MEMBER PARTRIDGE: That is not
likely to be true in other parts of the
country.

MEMBER FISHER: We don't see
hardly any of that.

MEMBER PARTRIDGE: Right. If you
were -- you know, that springs to mind because
of my own experience, but I'm sure there are
other characteristics and environmentally-
caused conditions and so on.

MEMBER FISHER: One other thing is
I was looking at the citations they gave and
we were talking about risk adjustment, but
it's interesting in the citations that they
gave for the group that they are talking
about, they were dividing them into subgroups
for comparison.

CO-CHAIR HOMER: Right. You can
do that.

MEMBER FISHER: Yes. And so the
question to me that is very important when you
are looking at this. And they even, you know,
bring it up when you look into the system.

CO-CHAIR HOMER: Right. And so I
mean even as we are speaking I'm sitting here
stratifying the national data or the
Mississippi data by raising things like that.

MEMBER FISHER: Yes.

CO-CHAIR HOMER: So one could
certainly do that. Okay. So I'm still
hearing a lot of concern about the
scientific --

MEMBER FISHER: That raises
poverty.

CO-CHAIR HOMER: -- validity and
the scientific merit of the measure.

MEMBER JENKINS: Specifically
around confounding by the individual patients
that are part of the numerator.

CO-CHAIR HOMER: Okay. All right.
Any other elements? That's the scientific
credibility. It sounds like we have got a
clear sense.

DR. WINKLER: We should vote on
it.

CO-CHAIR HOMER: Should we vote on
the whole measure based on that?

DR. WINKLER: Each criterion.

CO-CHAIR HOMER: Okay. You want
to talk about usability next?

DR. WINKLER: We need a vote from
the Steering Committee on each of the major
criteria.

CO-CHAIR HOMER: Okay.

DR. WINKLER: Going out.

CO-CHAIR HOMER: We haven't
consistently been doing that.

DR. WINKLER: You haven't gone
through them yet. You haven't got that far.

CO-CHAIR HOMER: Okay. So then on
the scientific merit, all those who believe it
has sufficient scientific merit to move
forward?

DR. WINKLER: Yes, completely.

CO-CHAIR HOMER: Completely?

MEMBER JENKINS: Does it have to
be completely?

DR. WINKLER: No. You have
choices, remember?

MEMBER JENKINS: Well, what are we
voting on?

CO-CHAIR HOMER: So we are voting
on the scientific merit of this measure and it
needs to be at the completely. Does it completely fulfill the criteria for scientific?

MS. McELVEEN: And the choices are completely, partially, minimally, not at all or not applicable.

CO-CHAIR HOMER: Right.

DR. WINKLER: So I get zero for completely. How about partially meets the criteria?

CO-CHAIR HOMER: I'd say partially.

DR. WINKLER: One, two, three. Marlene?

MEMBER MILLER: I believe minimally.

DR. WINKLER: Okay, fine. So that's three for partially. How many are minimally? One, two, three, four, five, six, seven, eight, nine, ten, eleven, Marlene is twelve. Okay. That's it.

CO-CHAIR HOMER: Moving on to the next criteria, which is usability. And the
subsets for --

MS. McELVEEN: We have to go back
to the --

CO-CHAIR HOMER: So does it
provide meaningful, understandable and useful
information?

DR. WINKLER: Right.

CO-CHAIR HOMER: Yes, I mean, the
sub-categories here are meaningful,
understandable and useful information in
relation to other NQF-endorsed measures, level
of harmonization, distinctive and added value,
right, those are the --

DR. WINKLER: Yes, those are them.

CO-CHAIR HOMER: Those are the
subsets of that.

MEMBER CLARKE: I would say that
actually mixing the scientific merit really
kind of makes this sort of moot.

CO-CHAIR HOMER: The rest is sort
of moot.

MEMBER CLARKE: And it may be that
we could have a discussion about is there a stratification fix for the scientific merit that we could stipulate.

CO-CHAIR HOMER: That's a good idea.

MEMBER JENKINS: I agree that they are correlated and that, to me, this whole thing was a lot about usability, which is about actionability and to the same extent that we had trouble understanding the subpopulations of the measure, et cetera, it fell down to be in the usability action ability.

CO-CHAIR HOMER: But going back to David's question, are there recommendations that we could come up with as to how this measure could be fixed, so that it could, in fact, be usable and provide what you would consider valid data?

I mean, what kind of stratification variable, for example, would you want to know in order to do this?
MEMBER CLARKE: Diagnosis and activity expectations.

MEMBER JENKINS: And potentially the extent to which those are modifiable. I think that there is ways through either exclusions or through categorizations that one could craft a very interesting outcome measure which is much more actionable. It would be some work for them to do it.

CO-CHAIR HOMER: Yes, I'm wrestling a little with, you know, the movement in the field for kids with special health care needs has been to the sort of non-categorical approach that is that the issues around the care and to some extent outcomes, but the care of kids with chronic illness is more common across conditions. And the use of diagnostic categories is usually pretty poor in identifying kids.

MEMBER JENKINS: If I could say, and I'm sure you will see some of this in our
measures tomorrow, that you can sometimes
group patients together or children together
in categories for the outcome of interest --

CO-CHAIR HOMER: Yes.

MEMBER JENKINS: -- regardless of
diagnosis. So here the issue has to do with
more of the expectations of the effect of the
condition on the lifestyle and the trajectory
of disease and the ability to impact that by
medical treatment.

So regardless of diagnosis, those
are really the categories that would be
necessary to understand the variation in the
outcome. They may not be by diagnosis or they
may.

CO-CHAIR HOMER: Okay. I guess I
take from that actually that it would be a
quick fix of this measure is not likely, that
that's actually a pretty complicated set of
questions.

DR. WINKLER: Yes.

CO-CHAIR HOMER: Okay. So I think
so let's then keep -- so that we can check off all the check boxes, make sure that we have gone through the usability criteria.

Why don't we call a vote on how many feel it meets completely usable?

DR. WINKLER: Marlene?

MEMBER MILLER: Yes?

DR. WINKLER: You're not voting completely, are you?

MEMBER MILLER: No, I'm not.

DR. WINKLER: Thank you.

MS. McELVEEN: Next one?

CO-CHAIR HOMER: Partially usable?

Partially usable, anyone?

DR. WINKLER: Okay.

CO-CHAIR HOMER: Minimally?

DR. WINKLER: One, two, three, four, five, six, seven, eight, nine, ten, eleven, twelve, thirteen. Marlene?

MEMBER MILLER: Yes.

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

CO-CHAIR HOMER: And not at all.
DR. WINKLER: And you're the not
at all. Okay.

CO-CHAIR HOMER: All right. And
then the last one is is it feasible? Data
generated by product of care or other
electronic sources, appropriate specifications
of exclusions, susceptible to inaccuracies?

And I guess I would argue that if
this is actually just derived from the
national survey, it is actually extremely
feasible, because the federal government
produces the survey on a regular basis and
there is an online data query tool that anyone
who wants to get it at this population level
can get it.

So that would be -- so those who
feel it is completely feasible? Completely
feasible?

MEMBER FISHER: Okay. All right.

MS. McELVEEN: Show of hands?

Those who say completely feasible hands up
high, please? Thanks. All right. Nine, ten.
CO-CHAIR HOMER: You should be strong.

MEMBER LIEBERTHAL: Just a comment. It is feasible to do, but just because it's feasible, what do you do with it once you get it?

CO-CHAIR HOMER: Well, that's the --

MEMBER LIEBERTHAL: And we are inundated with data that is feasible, but then you have to figure out what to do with it.

MEMBER FISHER: Yes, but it's still feasible.

CO-CHAIR HOMER: Fair enough. We are just trying to say that these are somewhat distinguishable categories. We are trying not to do the global subjective judgments.

MEMBER DOCHERTY: My only problem with the feasibility category is the inaccuracy piece of it, that it is hard to say something that has some potential for inaccuracy --
CO-CHAIR HOMER: Yes.

MEMBER DOCHERTY: -- because of the way the question is worded and the denominator then can be feasible.

CO-CHAIR HOMER: Okay. So we have how many said --

MS. McELVEEN: Ten.

CO-CHAIR HOMER: 10. So let's move on to partially.

DR. WINKLER: One, two, three.

MEMBER MILLER: I'll vote partial.

CO-CHAIR HOMER: Okay. So we have four, five. We have five. So that means that no minimally and no -- did I get that right?

No minimally and no not at all.

So do we need an overall vote?

DR. WINKLER: Yes.

CO-CHAIR HOMER: We do need an overall vote. So how many would vote in favor of recommending this measure to go forward?

It's out of order. No, that's fine. I see none in favor. How many who vote no, not to
recommend it going forward in this current state?

MEMBER MILLER: I'm a no.

CO-CHAIR HOMER: Okay.

MS. McELVEEN: Okay. We fully got through one measure, so we are moving along well.

CO-CHAIR HOMER: Moving right along.

MS. McELVEEN: Lunch is set up in this room exactly where the breakfast was set up. So we are going to take about a 15 minute recess. If you could get your lunch and eat, phone calls or whatever and come back, and we will reconvene.

(Whereupon, the meeting was recessed at 12:45 p.m. to reconvene at 1:30 p.m.)
1:30 p.m.

CO-CHAIR HOMER: All right. Well, why don't we reconvene. I hope everyone enjoyed their delicious lunch and had a chance to chat. The food was very nice. The sun is shining. This is good.

We do have a number of guests that we haven't had the chance to say hello to. I wonder if our guests, that maybe some of us met during lunch, could just introduce themselves.

DR. BERGERSEN: My name is Lisa Bergersen. I'm a pediatric interventional cardiologist and I'm from Children's Hospital, Boston.

CO-CHAIR HOMER: Thank you very much.

DR. RAUSCHER: Hi. Nina Rauscher. I'm also from Children's Hospital, Boston. I'm the measure steward for the four measures that are going to be presented tomorrow.
Thanks.

DR. DEINARD: I'm Amos Deinard from the Department of Pediatrics and School of Public Health at the University of Minnesota.

CO-CHAIR HOMER: That is a perfect segue. Thank you for being here. The first measure that we are going to review this afternoon is the one that you were the --

DR. DEINARD: That's why I'm sitting at the head of the table right now.

It was all scripted.

CO-CHAIR HOMER: So this measure is OT3-049. It goes by the name of Primary Care Prevention Intervention as Part of Well Child Care. This measure was reviewed by Work Group 1. The scores are reflected on the board. Would anyone in Work Group 1 like to talk this one through?

MEMBER MILLER: Charlie, what's the number of it again?

CO-CHAIR HOMER: Forty-nine.
MEMBER CLARKE: As far as impact we felt it is a condition that affects a large number of children. There is pretty good evidence that fluoride varnish has a very positive effect in reducing Caries disease.

Obviously this is a significant problem a lot in low income populations. I guess one of the reviewers identified the issue that it's not real clear how available the fluoride varnish is to PCMPs but it must be fairly available, I guess.

DR. DEINARD: Would you like me to answer that? I can provide anyone in this room who sends me his or her email address with a list of vendors who will sell to medical clinics, public health nurse agencies, etc., without any questions asked. It's readily available.

The more you buy the lower the price. It's got a two-year shelf life. You can buy it in good-size labs for 85 cents a dose or something like that. It's very
inexpensive. It takes less than five minutes to put on. In many states it can be delegated to a CMA or an LPN or a MA to actually do the varnishing.

MEMBER CLARKE: Do we have to vote on impact?

CO-CHAIR HOMER: We do. The work group felt that this was important that there was a gap in performance, at least either completely or partially and that the treatment related to outcome. Are there any questions from anybody about the importance?

MEMBER LIEBERTHAL: Yes, I do. What was the -- did the ADA have a policy statement on this? Unfortunately I would have to go to the AAP site because I don't remember if the AAP has a policy statement on this.

DR. DEINARD: The AAP not only has a policy statement that physicians should be doing this but it also has an oral health initiative group, one of the top three projects of the AAP this year and I'm a member
of that oral health initiative going state to state to help states get up and running.

MEMBER LIEBERTHAL: But AAP is recommending the fluoride varnish?

DR. DEINARD: AAP is recommending the fluoride varnish, as does AAFP. They are both referring to the ADA policy which now says that varnish should be applied quarterly to the teeth of high-risk children starting at age one.

A high-risk child can be very simply defined as a Medicaid child or a CHIP child who does not have a dental home, i.e., a home where the child can go for dental care whenever there's a problem and regardless of what the problem is.

A lot of mothers will say, "I've got a dentist," but that was to have one tooth pulled and the dentist won't see the child again. Biggest problem today is the dentists generally don't want to see Medicaid or CHIP children. They will turn their backs on them.
unlike physicians who must.

If I don't want to take care of a patient, I'm obligated to triage that patient to somebody else. Dentists seem to have no compunction whatsoever to turn their backs and say, sorry, I don't take Medicaid. Good bye, without any questions asked about triaging and it's a national crisis. The opening words to the Surgeon General's Conference in 2000 were the mouth is part of the body and that was echoed over and over again for three days.

CO-CHAIR HOMER: So I think, just to stick to the process, outstanding content, but just to stick to the process just in terms of a vote on importance. All in favor of saying this is sufficiently important to go forward or meets the criteria completely, I guess, is the question.

DR. WINKLER: Is Marlene still with us?

MEMBER MILLER: I'm here. I vote I guess completely.
DR. WINKLER: Okay, yes. All right. Great. Thanks.

CO-CHAIR HOMER: So that is how many for completely? Everybody. Okay. So we will dispense with the other categories. All right. Moving into the scientific acceptability of the measure. David.

MEMBER CLARKE: I think everything was pretty good with the science of it. I didn't really come across any problems that I had. I don't know if any of the other reviewers did.

CO-CHAIR HOMER: I actually did have a question somewhere between the scientific and probably on the feasibility side. You mentioned that the only exclusion is if the child has a dental home and I wondered how that could be obtained through the kinds of data.

I saw a mismatch between basically this could be easily collected in a valid, reliable way from encounter data and you've
got this concept of the dental home which is
do you have access --

DR. DEINARD: The primary care of
prevention and intervention in my mind has
five pieces to it; a physician, family
medicine, pediatric, nurse practitioner,
physician assistant, public health nurse. In
Minnesota there are more EPSDT exams done in
greater Minnesota by public health nurses even
than by family medicine docs. They do a lot
of them.

So gross examination of the teeth,
eye balling. Not with a probe and x-rays as
the dentist uses but eye balling it. If it
looks like a train wreck, try to find a
dentist who will tell you either it's a
variant of normal or a train wreck. If it's
a train wreck, the dentist will hopefully fix
it.

The second is a risk assessment,
paper and pencil, 30 seconds. There are a
number of risk factors: the mother's oral
health status, the siblings' oral health status, do they have a toothbrush, do they use fluoridated water, fluoridated toothpaste, etc.

But if the child is on Medicaid or CHIP and has no dental home, that child is high risk. If you're high risk, according to the ADA recommendations, you should get the varnish four times a year.

The third part of the intervention is anticipatory guidance to the care giver which is every bit as important as the varnish in telling the care giver (a) the ideology of caries and then (b) the care giver's role in prevention of caries.

If the mother continues to (a) lick the pacifier with her own saliva before she puts it in the child's mouth, and I've seen that 10,000 times if I've seen it once when the sink is right at the mother's elbow and she prefers her saliva, all she's doing is moving strep mutans from her mouth to the
Strep mutans is the principal organism that metabolizes the sugars that come in the bottles that the mother is feeding the child all day and all night long. The bug digest the sugars for its own metabolic purposes.

Its excrement is acidic. The acidic excrement etches the enamel of the tooth and the caries process is started. The mothers need to understand the dynamic here. It's insufficient to say don't put the kid to bed with a bottle. There's got to be an explanation why not or the mother will pay no attention. That's the third part.

The fourth part is putting the varnish on four times a year. The fifth part, according to the Academies of Pediatrics and Pediatric Dentistry every child should have a dental home by age one so you should still try to find one even though you know full well that it happens very infrequently.
That is one of my complaints about the dental element of the EPSDT exam that CMS has articulated. All you have to do is put in the chart "made a referral to the dentist." It will fail a hundred times but you'll pass audit a hundred times and you've done nothing for the child as a consequence of telling the mother to find a dental home.

CO-CHAIR HOMER: I couldn't agree with you more. You weren't here first thing in the morning. Marlene Miller said we should have a change package with every measure and you've articulated the change package. But we are voting on the measure so I need to know more about --

DR. DEINARD: The measure is if the child gets varnished, presumptively the child is high risk, the Medicaid child. From the claims data, at least in Minnesota, the claims data I have a report that I get and now I've gotten two reports, 2008 and 2009, that shows the billing entity, either the clinic or
It shows three columns: zero to five years of age, six to 12, 13 to 20, but that could be subdivided any which way. It shows duplicated and unduplicated EPSDT exams by provider type and duplicated and unduplicated fluoride varnish application by provider type.

This goes across the page so I can see that Dr. X had three children who got an EPSDT exam. He did eight in total on those three children. He put varnish on one child one time. That's the kind of report that I can get from the state.

CO-CHAIR HOMER: So what is the measure that you are proposing?

DR. DEINARD: The measure that I would like to track is that physicians have a primary role in caries prevention by virtue of the fact that children can't get dental care. Therefore, one way to try to prevent caries is to put varnish on and presumptively along with
the varnish goes the education, etc.

Like anything else in pediatrics we do anticipatory guidance on a whole range of topics. We do risk assessments across the board and we are always giving advice trying to keep something from happening before it happens.

CO-CHAIR HOMER: I'm trying to help here. I want this measure -- I personally sit on the board of an institute that focuses on improving this kind of work. I'm trying to help get a measure that we can decide on its scientific merit and I need a definition. I'm thinking not as an advocate and not as a pediatrician who cares about kids. I'm trying to think as a measurement sort of person. Tell me what the numerator is.

DR. DEINARD: The numerator is the number of children who got varnish duplicated. How many varnishings went on all the children who had an EPSDT exam. The denominator is the
number of EPSDT exams done. If every child gets a varnish every EPSDT visit, or at least on a quarterly basis, then the number of varnishes should equal the number of EPSDT exams done.

CO-CHAIR HOMER: So the numerator is the number of varnish applications?

DR. DEINARD: Yes.

CO-CHAIR HOMER: And the denominator is the number of EPSDT evaluations.

DR. DEINARD: Yes. Ideally it should be one to one, every time a kid comes in. Now, for the very young child who may come in -- what was the question?

CO-CHAIR WEISS: Is it varnish applications or is it children? What's the numerator?

DR. DEINARD: The numerator is the total -- well, you can look at it two ways. The number of unduplicated children who had an EPSDT exam is the denominator and the number
of those kids who got one or more varnishings.

CO-CHAIR HOMER: That's a different measure.

DR. DEINARD: The other measure is the total number of varnishes done as a function of the total number of EPSDT exams done.

CO-CHAIR HOMER: So, again, are you recommending -- I don't mean to be grilling and please forgive me.

DR. DEINARD: That's okay.

CO-CHAIR HOMER: This is a developmental process for us as a committee and I think for the people who are proposing measures to us. What I hear actually are that you are proposing two measures. One is the number of varnish applications divided by the number of EPSDT exams. The other is the number of children who had one or more varnish applications over the number of children who had --

DR. DEINARD: Who had one or more
EPSDT exams. That's the unduplicated number.

CO-CHAIR HOMER: Okay.

MEMBER JENKINS: And where does the concept of the dental home come in?

DR. DEINARD: Presumptively if a child has a dental home and is seeing the dentist twice a year because dentists get paid for the procedures they do and not for just doing an exam. You can be very certain that that child got varnish at each visit.

MEMBER JENKINS: Would that be an exclusion from the denominator or not?

DR. DEINARD: In a pediatric practice if I have a patient who is seeing the dentist regularly, mother says, I go to the dentist twice a year, then they get varnish twice a year. Fine.

I would say you're high risk. The other two times a year I'll do the varnishing because the dentist won't even get paid if he does more than two. The physicians will get paid, at least in Minnesota, for as many
applications as they want to do. Each state is different in that regard.

CO-CHAIR HOMER: In Minnesota how would you know to take those kids out of your denominator right now or just you just sort of say it's so small --

DR. DEINARD: I would say it is so small and then I could also by virtue of the number of kids who got an EPSDT exam go to the database and ask how many dental visits did you pay for this year? I mean, it's a very small number. That's the problem. There are too few dentists seeing all the kids that carry the risk.

It's just a way of saying you don't need it four times a year. If you've got a home, get it at least twice a year at the dentist and twice at the doc. But if most of these kids don't have a dental home, you get it four times a year at the doc.

CO-CHAIR WEISS: Given the population that you've chosen to focus on,
Medicaid and CHIP, and the presumption that very few of these children have a medical home --

DR. DEINARD: Dental home.

CO-CHAIR WEISS: Excuse me, a dental home, the two most important measures here are the number of applications over the EPSDT exam number and the number of children over EPSDT exams. Correct?

DR. DEINARD: Yes.

CO-CHAIR WEISS: And then we are working toward the idea of a dental home for everybody.

DR. DEINARD: Yes, but it will be a lot easier to get the docs to put varnish on than wait for that dental home to arrive for everybody. That's a long wait.

MEMBER LIEBERTHAL: I have a question here. I don't know about Minnesota, but in California EPSDT is not four times a year. EPSDT exams occur once a year other than for the children under two who follow the
AAP schedule.

Without questioning the value of the fluoride varnish and the number of fluoride varnishes that is ideal and just looking at a measure that has to be clearly defined, it would seem to me that if you are correlating for a varnish with EPSDT exam, that should be the measure with the numerator being fluoride varnish and the denominator being EPSDT exam.

DR. DEINARD: Unduplicated.

MEMBER LIEBERTHAL: What do you mean by duplicated?

DR. DEINARD: If one child comes in and gets the treatment once, it's one and one, duplicated and unduplicated. If one child comes in and gets it four times, it's one child with four applications and the duplicated part is the four.

MEMBER LIEBERTHAL: But if your recommendation is four applications a year, I don't see the value of using the duplicated or
unduplicated. The relationship is that --
again, it depends on the frequency of the
EPSDT exams, which in California is not four
times a year.

DR. DEINARD: You could also since
the children are coming in hopefully to an AAP
schedule that calls for a certain number of
well child exams over the first five years of
life, you could also take CPT code for the
well child exam as well as the CPT code for
the EPSDT exam.

MEMBER RAO: That was the question
I had. Why link it to EPSDT exams at all?

DR. DEINARD: Because when CMS
comes into audit they take a look at how many
EPSDT exams you do and have you met all 13
expectations of the EPSDT exam. In my view
having been trained in the dark ages an EPSDT
exam is another name for a well child exam

Yes, sir.

MEMBER McINERNY: However, in many
states, Medicaid children are not getting
EPSDT exams at the recommended intervals and so you could have a Medicaid patient come in who is at risk who does not get an EPSDT but should have a varnish and, therefore, you've missed that patient because you didn't count that because they didn't have an EPSDT exam.

DR. DEINARD: What kind of encounter are you proposing that child have, just a well child exam?

MEMBER McINERNY: Well child exam.

DR. DEINARD: Okay. If that's the case in that state, I would say look at the number of well child plus EPSDT exams done and lump the two together as the denominator.

MEMBER McINERNY: I would exclude the EPSDT because they may not do the EPSDT but they might put the varnish on.

DR. DEINARD: Okay.

MEMBER McINERNY: Furthermore, they come in at a year of age, 15 months, 18 months, two years of age. The next one isn't until age three.
CO-CHAIR HOMER: If I could interrupt to take the Chair's prerogative, this has been a very rich conversation where we have learned a lot about issues around varnish, EPSDT, etc. It seems clear to me in the conversation that we don't actually have a measure that is highly specified because, again, as you said, we could define it this way, we could define it that way.

We could have this numerator, we could have that numerator. All of those may be useful but we as a committee I would argue my personal opinion that we actually don't have a specified measure that we can discuss and vote on so by this scientific acceptability the first thing is there is specifications.

I think we are not there yet. Therefore, it becomes very challenging for us to even make an assessment against the other criteria of scientific acceptability such as reliability, validity.
There is confusion here about exclusions because we don't have a consistently -- the idea with an NQF measure is that you have a measure that is highly specified so that not only in Minnesota but in Rochester, New York or in Florida or Washington State that you could take this measure, follow the numerator, follow the denominator, and come up with a comparable --

DR. DEINARD: But you're making an assumption that every state behaves like every other state. In Minnesota they do lots of EPSDT exams. If in another state they fail to code it as an EPSDT but code it as a well child.

CO-CHAIR HOMER: Then we would need to develop specifications, in my view. Anyhow, that was my assessment and I said that in part to see if we could accelerate or come to some closure around this section of the conversation.

Kathy.
MEMBER JENKINS: Charlie, I agree with you and I'm also noticing, as Ellen is as well, that it is, in fact, a process measure. It might be an excellent process measure that we could craft into that CHIPRA thing that we talked about at the beginning which might be a real value in the country for the CMS population.

I would also note that organizations like NACHRI can take help with the gap here to craft a measure that might work across the country. We could hold the thought today but get a much better thought before too long.

MEMBER McINERNY: That's a good point. I mean, the outcome measure is the number of children with caries who are on Medicaid.

MEMBER JENKINS: I know that we've tried with our dental group to craft a caries measure. They are very difficult to do. They may work at the population level but there is
another one that is not going to fold downward
but the process measure here is very, very
important.

CO-CHAIR WEISS: Let me also say
that for many years there have been problems
with the content of the EPSDT visits and so
while in Minnesota you appear to be very far
along in terms of the number of visits and so
on that are expected, it would not be a bad
idea to think about correlating a varnish with
an EPSDT visit just to be sure that the
varnish is, in fact, incorporated into that
treatment package.

DR. DEINARD: I would be perfectly
content to say that the denominator is a well
child exam. In Minnesota, I know I can get a
report of those who had well child exams and
those who had EPSDT exams. The question is,
state by state, no matter what kind of well
child care, you can put varnish on as part of
an ill child visit. It doesn't matter.

By the way, you start putting the
varnish on with the eruption of the first
tooth or by age one. Kids come in starting at
two weeks, two months, four months, six
months, nine months, 12 months so there are
lots of opportunities in that first year of
life to put varnish on at least at six and 12
months.

You can do it as part of an ill
child visit if you miss the child as part of
a well child visit. Or if the child fails the
well child and comes in ill and it's more than
four months since the last varnish you can put
it on.

You could take a look at your
varnishes as broken up in three ways: as a
function of well child care as a denominator,
as a function of ill child care because all
ill child visits have a code. The key thing
is that the code for varnish is a unique code,
D1206 in all the states but three and they are
using -- it's in the materials I presented, a
CPT code with a modifier.
Most of the states that are coming on board now, by the way, come July 1 there will be 37 states that are reimbursing, not 35. Progress is being made and Alaska and New Hampshire are right on the edge of joining the blue states.

You could set three different denominators. The question is as part of those encounters are the physicians doing what they could and perhaps should be doing in the way of oral healthcare for that child by putting varnish on?

CO-CHAIR HOMER: I would say Kathy's point though, one, this is a process measure which means we should revisit it when we are revisiting process measures. Number two is I would say for us to truly consider this as a process measure we will need more detailed specifications and actually some probably greater test data that says this actually performed this way in these settings so that we could actually get some experience.
That is where I'm thinking going forward. Why don't we just follow the process and keep Reva and Nicole happy by making sure that we vote on the different criteria that we need to do unless we want to just table it. I guess that is another option.

DR. WINKLER: Or, Charlie, you could kind of bypass this and basically say that being it's a process measure it's sort of out of scope for this but we really would like to see a tighter specified version in the next phase when we are really addressing the CHIPRA measures. That is an option.

CO-CHAIR HOMER: I'm seeing a lot of head shaking around the room. I would like to make sure staff has the opportunity to speak with our guests and make sure and maybe give some examples of some other well worked up process measures so that we can provide help to make sure that this comes back in a timely basis so we can consider it effectively because it is one of the critical health needs
of children on Medicaid. Yes, Nancy?

MEMBER FISHER: Ideally in the ideal world what would you want to see about varnish?

DR. DEINARD: In an ideal world for the Medicaid CHIP child?

MEMBER FISHER: For anybody.

DR. DEINARD: Well, for those who can get -- if you take a look today at the caries, who has caries today? 30 percent of children. Who are those 30 percent? The Medicaid CHIP kids.

Mexican-Americans have more disease than the African-Americans who have more disease than the Caucasians and the Africans and the Southeast Asians and the American Indians close to somewhere between the Mexican-Americans and the African-Americans. I would like to see medical providers be putting varnish on according to the ADA recommendation four times a year for those populations.
MEMBER FISHER: Okay. What I'm trying to get at is, in an ideal situation we have standards, like for immunizations you get so many immunizations. You are trying to do it by a certain time. What I'm saying is that ideally would you like all kids that they have no fluoride in the water or something is to get fluoride varnishes before the age of two?

DR. DEINARD: Starting at six months or the eruption of the first tooth.

MEMBER FISHER: Okay. I'm just trying to give some space for, you know, you've got time to get it in there. Would a goal be to start out I would like to make sure all kids have four by the age of two, by the age of 18 months? Something that was realistic. It could be done and it gets us on our way.

DR. DEINARD: I would like to see every child get four in the first year of life starting with age one to age two, another four between age two and age three, and all the way
up to age 20 because teenagers are rotting their teeth out drinking Coke all day long.

MEMBER FISHER: I understand that but I'm saying that we've got immunization things and we know we aren't getting some of them until they are teenagers. I just want to get a specific goal. If you tell me you want two by the age of -- what did you say -- two or four or something like that?

DR. DEINARD: I think four by the age of two on those who are high risk. Immunizations go to all children. This is for the high risk kids who don't have dental care.

CO-CHAIR HOMER: So just to wrap up the conversation, I do think if you think of the immunization measures, a great example, children across the country have to meet the same immunization standards regardless of whether you have a lot of EPSDT or you don't have a lot of EPSDT or whatever it is.

As we are reworking this measure, as we are working with staff on this, we want
to come up with criteria so that there is a
universal measure against the universal
standard that would apply in every state
because that is really where our charge, NQF's
charge, and also the CHIPRA legislation is
moving to having standard consistent
measurement across states so that we can
compare performance and make sure that kids in
Minnesota are not the only children in the
country protected against dental caries. I
guess I would propose that wrap-up.

DR. DEINARD: If what you want to
do is table this today, that is perfectly fine
by me because I can see this is not going
where I was hoping it would go; namely, that
you would say this is really good stuff and
it's important because NCQA will pick up on it
and CMS will pick up on it and there will be
something going forward.

CO-CHAIR HOMER: I don't want you
to get --

DR. DEINARD: To go two, three,
four years on process is two, three, four
years with kids not getting what they should
be getting.

CO-CHAIR HOMER: No, I don't want
you to get the message that we don't think
this is critically important because we do.
I think there is a lot of excitement around
the room about the importance of this and
there is the belief that -- our committee is
going to be calling for process measures and
reviewing them or seeing them in July so we
are not talking like six years from now.

We are talking about a couple
months from now, but you actually have a fair
amount of work to do to develop greater
specifications for this for it to be able to
pass. I mean, it doesn't go from our mouth to
God's ear.

It's got to go through additional
levels of review and commentary so it's really
friendly advice to come back with something
that we know is going to be able to pass
muster because this is an important topic that we want to see.

DR. DEINARD: What concerns me is that when you start looking at how states differ, why should that be any less important when you look at process, which is what we are looking at here today. Someone will say you do it this way in this state and this way in another state and we can't compare apples and oranges. There is no comparability.

CO-CHAIR HOMER: You could define encounters for either well child or EPSDT in such a way or you could say all children by the -- we can talk offline. This isn't the committee in which we should actually develop the measure.

MEMBER FISHER: Can I just make one more comment? The reason why I asked for something that was standard for all kids is I'm thinking about the practitioner who is out there. It's much easier to keep it simple. I mean, I can't memorize now all
the immunizations but when I was really doing them I knew them and I didn't look at somebody whether they're poor or rich or Medicaid. You got an immunization, you know, so that's all I'm trying to do is keep it simple, get it into the practitioner's head you need this and you get it by a certain time.

DR. DEINARD: The difference -- MEMBER FISHER: And just because you're rich doesn't mean that you don't get cavities. It just means you can have them filled.

DR. DEINARD: The difference is that all medical insurance will pay for immunizations across the full socioeconomic spectrum. Medical insurance today will not pay for this on the commercial side. This is only the Medicaid program in 37 states that said they will pay. The others are still in the works.

If you have a lot of kids who are commercially insured on the medical and you do
this and you bill the medical side, you're
going to get denied and then you are going to
have a lot of angry parents saying, you didn't
tell me this was going to cost me money and
not covered by my insurance.

Offer it to them and charge them
for what you charge Medicaid because you would
like to offer one thing to everybody. For the
medically insured you offered it at a price
that the mother pays or doesn't pay.

To say we are going to give it to
every kid, you are going to have bedlam in the
offices where you've got 50 percent of the
commercially insured and Medicaid insured.
There is going to be a lot of bills and
charges unpaid and parents will be very
unhappy.

MEMBER FISHER: Some places people
have dental insurance and then I think the
other thing is that we get a standard and we
have to think of how we can get that paid.
Anyway, that's all I have to say.
DR. DEINARD: Dental insurance will not reimburse the physicians because they are not credential with the dental insurers.

MEMBER LIEBERTHAL: At risk of prolonging the conversation that's not the direct topic of this meeting, I think you are aware of the implications of what you are saying, four varnishes a year for all children has huge implications with regard to frequency of visits and cost of medical care that have to be addressed.

That really isn't the province of this committee. As you formulate this I think you have to be very aware that a combination of four visits a year to a dentist and to a physician is not the standard of care.

DR. DEINARD: Well, from the medical side when you get over age two and children only come in for well child care once a year, just like you run immunization clinics you can run fluoride varnish clinics. The CMA puts it on and you're out the door.
CO-CHAIR HOMER: Any last comments?

MEMBER PERSAUD: Just two last comments. One place you might look at when you are looking at the states I think part of the opportunity here is to come up with some reasonable standard that would influence practice, or rather best practice in states and performance of Medicaid and CHIP systems in paying for things that are going to be ultimately effective.

You might look at Texas. We are rarely ahead on anything but as of two years ago we began making the referrals to dental homes at six months and started varnishing at nine months either by us or by the community dentist.

I believe that the rate of children reaching the dentist for the first time between one and two years of life has proportionately increased since we did that. I think there are opportunities here for you
in developing the measure to come up with what should guide best practice.


MEMBER JENKINS: A process question, Charlie. It seems obvious to me that -- I'm sorry. I don't know your name but in order to meet the standard of the process application in July could use a little help. How does that work? Who is going to help?

MS. McELVEEN: It would essentially be staff, of course, guided by you all if you have specific recommendations that you can provide to him that we can then work with him to do. You have identified some of those here throughout your discussions today.

CO-CHAIR HOMER: Thank you very much. I know this was not the result you wanted but I think we will end up where you want to be.

DR. DEINARD: Well, I hope you're right.
CO-CHAIR HOMER: So let's move on to the next measure on our list and we are going to go back to -- oh, is there a public comment?

MS. McELVEEN: We usually allow the audience to come up but we don't have any audience.

CO-CHAIR HOMER: Okay.

MS. McELVEEN: I wanted to get feedback from the group. The next measure that is up for discussion is that larger survey measure that has 22 individual measures comprised within it.

I think based on our previous conversations it would probably be safe to say to table that for now and maybe look at the individual components first. Are there any objections to doing it that way or does anyone have any further comments?

CO-CHAIR HOMER: Sounds like a good idea.

MS. McELVEEN: Okay. So that
takes us to -- sorry. Let me just pull up the
table here. This is Work Group 3 and the
measure we will be discussing first is 32.

Measure 32 again was part of a
larger survey measure. This single measure is
the number of school days missed due to
illness and the description measures the
quantitative number of days of school missed
due to illness or condition among children and
adolescents age 6 to 17 years of age. We
should probably start with an importance
discussion as we have been doing with all of
our measures.

CO-CHAIR HOMER: So anything from
on the Work Group 3?

MS. McELVEEN: Unfortunately we
only have two of the members who were assigned
to this work group present with us today.

CO-CHAIR HOMER: Allan?

MEMBER JENKINS: This is a measure
from the other major survey, the National
Survey of Children's Health. We alluded to it
this morning. This is one question on the survey, the number of school days missed.

In terms of the importance, this is widely regarded, I believe, as a very important outcome measure that rolls up a lot of aspects of child health. It's a relatively simple measure. It's done by asking the parent how many school days were missed over the last 12 months due to illness or condition.

I thought it passed the importance criteria. There is also some data in the application about the gap and variation, although if I remember correctly, that was presented as more than two weeks of school missed.

Allan, I don't know what else you would like to say to introduce this in terms of an importance discussion.

MEMBER LIEBERTHAL: I agree with you completely on importance. I had some issues with it regarding some of the other
criteria but it certainly is an important measure of public health.

CO-CHAIR HOMER: Any other discussion about the importance?

CO-CHAIR WEISS: Charlie tells me that researchers use this measure. I would just like to know a little bit more. Who looks at this and how is it used?

MEMBER JENKINS: I can tell you that we're using it at the Children's Hospital in Boston as a measure of effectiveness as an asthma community health program and that all of the process measures of asthma care every time we discuss them people reminded everyone that they were process measures and not outcome measures and this was the one that always rises to the top as the outcome measure of interest.

If we could reduce the number of school days missed from our asthma community health program that we would be making a difference in the asthma population.
MEMBER LIEBERTHAL: We use that, too. I believe NHLBI in their impairment part of the NHLBI guidelines includes days of school missed and function when they are not having an acute exacerbation.

Also in my general practice when I'm dealing with kids with a variety of illnesses, and especially children who have what turn out to be psychosomatic illness such as frequent headaches, frequent abdominal pains.

One of the important questions I ask is how many days of school are you missing because that may give me some idea of how much impact these symptoms are having on the child's health.

CO-CHAIR WEISS: But in both cases you're relating school days missed to a particular condition or a particular diagnosis. Right? Is that picked up in this measure? I don't think that it is.

MEMBER LIEBERTHAL: No. That's
one of the problems is we get to scientific acceptability, usability, and feasibility.

CO-CHAIR WEISS: Okay.

CO-CHAIR HOMER: So, again, just from the process perspective does it meet the threshold for importance criteria? All those who feel it completely meets the criteria, please raise your hand.

DR. WINKLER: Marlene?

MEMBER MILLER: Yes.

DR. WINKLER: Thank you.

CO-CHAIR HOMER: That's everybody.

Okay. Now, moving onto the scientific acceptability.

MEMBER LIEBERTHAL: I can speak to that. It's a very imprecise question. The way it's phrased it just uses the term illness or injury and parents have different interpretation.

Also, many parents will keep a child home from school for their own personal convenience or for other reasons but they
attribute it to illness because it's more socially acceptable, just as many of our workers attribute their personal days off to illness.

Also, if you ask a parent, and I run into this a lot, if you extend it to how many days a child has missed in the past year, they are going to most likely generalize it from their most recent experience just as when they say, they are always sick. When you come down on it they have been sick every other month, not always sick.

If I get a child, again with asthma, he might have missed a week of school. Then I asked them how many days did he miss in a year. They either don't know or they guess based on the fact that he just missed a week so it really doesn't differentiate.

Also there is no differentiation of healthy children from children with special health care needs. I think there are a lot of problems that it is such a generalized
question.

MEMBER JENKINS: I agree. I had the same thought about the scientific issues associated with it. They did a good job with excluding children who were home schooled and that sort of thing. Exclusions were pretty well specified.

I thought they did actually stratify or exclude patients with special health care needs but, again, it's based on essentially a mother's recollection and writing down a number over an entire year and I thought there was very likely to be respondent bias in that.

Interestingly it is a measure that can be validated. The community medicine program I was alluding to earlier they actually use school records to count school days missed as opposed to mother's recollection of school days missed. It's not one of those where it's impossible to actually count school days missed from a different
MEMBER McINERNY: That was my question. Have people looked at the parents said the child missed six days of school in a year and then they go to that child's school record and find out they missed 3 days of school or they missed 12 days? Is there good correlation?

MEMBER JENKINS: There's no validity presented by the measure.

MEMBER ZIMA: School record data is complicated. I'm just going to say one thing and then say we won't go there. That is that you also have variation by the length of time a child's semester is and grading period and sort of picking what semester or grading period you are going to do and then adjusting it to the number of days for that grading period is a lot of work so that's one issue.

Then the other, I've got a question. I'm not sure because I'm concerned with the denominator including the word or
injury. I was wondering whether those around
the table who have thought about this thought
about having handled that part of the
numerator.

MEMBER DOCHERTY: I just wanted to
respond to the question about whether or not
parents can report the number of school days
missed. I general in research literature with
chronically ill or children with special
health care needs, parents are actually found
to be very reliable reporters of the numbers
of days.

I can't think of any citations off
the top of my head but we know that parents,
especially mothers, are very good at being
able to recollection symptoms, number of
symptoms, and the variety of repercussions of
the symptoms of their children's chronic
illnesses.

While there is absolutely no
perfect measure of this kind of thing,
obviously the school records are difficult to
get, I feel that mothers are pretty reliable
in terms of if you ask them to think back
specifically over the last month, and then the
preceding seasons were they any worse than
this past season, that they actually are
pretty reliable reporters of their sick
children.

I don't know about healthy
children. This is just research with
chronically ill children or children with
special health care needs.

CO-CHAIR HOMER: I guess I also,
again, when I looked at this literature in the
past and I wish, again, more information was
presented, one of the challenges in using
something like school records and one of the
reasons that having the illness or injury
question is useful is that really as, Allan,
you suggested, the major determinant of school
attendance has much more to do with maternal
functioning than it does with child health.

Obviously those two are not
unrelated. Twenty or thirty years ago Michael Weitzman did a series of studies looking at the utility of school days missed as an indicator of asthma performance and found that just using it on a global basis it was overwhelmed, at least at that point, by other measures of social dysfunction compared to illness management. I think that is why due to illness or injury sort of comes in there rather than just leaving it as a straight count.

And then I think -- I guess this is a legitimate question. If one is trying to develop an indicator that you are going to be able to use in multiple places in a feasible low cost way and somebody is doing the survey on a regular basis, it's not a bad way to go. Again, maybe that's more on the feasibility than the validity because there is definitely a trade off that you do remember things better more recent obviously. I love the way you did that sequential questioning of
last season but it doesn't look like that is how they -- is that how they asked the question?

MEMBER JENKINS: It's consistent across the whole survey using 12 months. Presuming that the respondent was in the mind frame of the survey it's consistent throughout all the questions.

CO-CHAIR HOMER: Any comment on any of the other elements of scientific acceptability that are worthy of note? Risk adjustment is not appropriate. There are differences that they reported.

DR. WINKLER: Just to clarify, you said risk adjustment is not appropriate?

CO-CHAIR HOMER: I was just looking at the scores that are up on the board.

DR. WINKLER: This just said that it doesn't meet the criteria.

CO-CHAIR HOMER: Oh, I'm sorry.

Thank you. I had a misplaced column there.
MEMBER JENKINS: I think it's back to that comment we made at the very beginning where across the entire country, across the entire survey with a percentage of patients with special health care needs missing school be different in various states or geographic regions. It's a potential confounder that may not be especially serious to understanding variation.

MS. McELVEEN: Just a clarification. This particular survey is not a component of the one for children with special health care needs.

CO-CHAIR HOMER: This is ultra.

MEMBER JENKINS: Right, it's ultra. I just wanted to make that clarification.

CO-CHAIR HOMER: Do you know if this survey includes the screener, though? Can you stratify? I would have to look and see and I'm not sure that's critical to answering this question. I thought it did.
All right. So can I have a vote on those who feel it completely meets the criteria for scientific acceptability?

Marlene?

MEMBER MILLER: Does not.

CO-CHAIR HOMER: Okay. Partially meets the criteria?

DR. WINKLER: One, two, three, four, five, six, seven, eight, nine, and

Marina is not here. Okay.

CO-CHAIR HOMER: So we'll get her when she comes in. Good.

DR. WINKLER: I think you need to put minimally.

CO-CHAIR HOMER: Minimally.

DR. WINKLER: One, two, three, four.

MEMBER MILLER: I say minimally.

DR. WINKLER: Okay. That's five for minimally with Marlene.

CO-CHAIR HOMER: And not at all?

Did you get everyone already?
DR. WINKLER: I think so with the exception of Marina. You're partially, minimally, not at all?

CO-CHAIR WEISS: Partially.

DR. WINKLER: Partially. Okay.

So that makes that a 10.

CO-CHAIR HOMER: All right. Let's move on then to the usability section.

MEMBER LIEBERTHAL: I just don't see what you are going to get out of this for improving care. Not because it's not an interesting number and not because it's not an important number. It's just that the measure is too broad to take any action based on it. You have to really subdivide it as to causes for school absence.

CO-CHAIR HOMER: Any other discussion of that?

MEMBER PARTRIDGE: I just want to say 100 percent agreement. I'm looking at this really from the perspective if I said to the parents in my community, we have a very
high rate of absenteeism in our school, the next question they would ask is, why? Do we have an epidemic of measles? What is it?

I would love a measure that was more specific to certain conditions. I would love a measure of a child that we think is being treated for asthma, that dimension. That would be a wonderful outcome measure but this is too broad.

CO-CHAIR HOMER: But didn't we -- I mean, we actually specifically put this on our list of things. We said we wanted measures of global outcomes including broad measures such as school attendance and we got what we asked for.

MEMBER JENKINS: This isn't a population-based measure. It's a very, very high-level look.

MEMBER PERSAUD: I'm thinking about things like during the flu season you may have huge absences but what that's going to reflect is that your threshold number of
children that you are immunizing in schools is not high enough and you need to do something about that.

I think it's a population measure and I think as a population measure it can be useful. It's not useful to the individual level or for a clinic performance but I think from a resource perspective and managing that population in a community, I think it is a useful measure.

MEMBER LIEBERTHAL: But you're addressing a specific time period. This is a 12-month measure so the fact that there is high absenteeism during the flu season could not be identified by this measure.

I agree that this measure if it were worded differently and not as broad would be excellent. In response to Charlie maybe we asked the wrong question.

CO-CHAIR WEISS: Let me just say that I'm not sure I'm convinced that as a population measure it's all that useful but,
you know, maybe I'm not thinking broadly enough. However, it strikes me that the providers of care, the clinicians who are sitting around this table, are almost to a person saying it is useful.

Sharon's point about parents who deal with a chronically ill child using it as a marker for how well their child's disease or condition is being controlled is very convincing to me that this is a useful measure even if it doesn't have utility for the mayor or the health commissioner generally.

MEMBER PARTRIDGE: I think I would feel differently if you said the class we're defining is children with special health care needs. That narrows it enough for me to make me feel that it has some usability. I'm not making Charlie happy.

CO-CHAIR HOMER: Well, because I'm doing queries right now and I can actually query right now for kids who have a medical home or don't have a medical home in Michigan
compared to Minnesota the number of days that
they are missing school. If I were a state
policy maker or whether you have a medical
home or not, you have given me some useful --

MEMBER PARTRIDGE: You've linked
it to a medical home.

MEMBER JENKINS: That's how people
would use it. If they found they were high on
this measure, they would then ask why and then
they would fall into various interesting
reasons why they were high on this measure.

CO-CHAIR WEISS: But as a stand-
alone measure it really isn't telling us a
whole lot at the general population level.

MEMBER DOCHERTY: It can be used
in statistical models with other variables to
explain more about what it's more predictive
of or what it's associated with other
variables so collect as a stand-alone measure
but then compared with other measure of that
population it could tell you more.

CO-CHAIR WEISS: Don't get me
wrong. I'm going to vote for this. I'm going
to vote for it because I think it does have
utility but in and of itself as a stand-alone
measure I honestly don't think that it tells
us very much that can be used on a population-
wide basis.

However, as compared to other
measures, the medical home being a perfect
example, and its utility for the practitioner,
and also with a parent with a child whose
function is being measured in part by how well
they are able to meet the scholastic kinds of
expectations, to me it has value.

CO-CHAIR HOMER: Nancy.

MEMBER FISHER: I was going to
say, though, when we talk about taking a
measure and looking at it at a higher level,
we already have that affirmation. It was
given to us in the evaluation of the measure
telling us how many kids with chronic disease,
I mean with special health care needs and
stuff. To me we have it at a higher level.
What we need is the measure that goes down deeper to tell us specifically. Like someone said, I don't know if you call it healthy kids but you would have something on kids with special health care needs, something on kids with chronic disease if we don't have that, and then the others that are supposed to be normal or whatever, average I guess you would say.

And then the kids with chronic disease what you'd want to know is which diseases and how it's keeping them out of school. That to me would be more helpful. Right now I think we have the information on a higher level. That's where they are justifying this measure.

CO-CHAIR HOMER: So help me with this. Yes, this measure is already available and you can query it on the website.

MEMBER FISHER: Yes.

CO-CHAIR HOMER: But I thought that basically NQF needs to certify or as CMS
going forward is going to say if you want to use this measure, for example, within your state for a variety of purposes; quality, measurement, and recording, it needs to be an NQF endorsed measure.

MEMBER FISHER: Okay.

CO-CHAIR HOMER: Even if we have it now and it's available and you say you want to use it or the secretary says she wants to use this when she's setting up comparisons or things that are around the national report card of how Washington State is doing compared to Oregon, it would need to be NQF endorsed.

MEMBER FISHER: Okay. That's different.

CO-CHAIR HOMER: Okay. So now that we've --

MEMBER JENKINS: Feasibility, I think. Right? Oh, we're going to vote.

CO-CHAIR HOMER: So let's vote on usability. Is it understandable, is it harmonized, and does it provide added value
basically over other things that NQF has already endorsed presumably.

DR. WINKLER: We haven't done anything like this

CO-CHAIR HOMER: There are no measures then?

DR. WINKLER: Nada.

CO-CHAIR HOMER: So how many folks feel this completely meets the criteria for usability? Shockingly enough. Okay, one. See, I didn't succumb to peer pressure.

Partially?

DR. WINKLER: Marlene?

MEMBER MILLER: I'm stuck between partially and minimally.

DR. WINKLER: Okay.

CO-CHAIR HOMER: And then minimally?

DR. WINKLER: Have you decided, Marlene?

MEMBER MILLER: I'll go minimal.

DR. WINKLER: Okay.
CO-CHAIR HOMER: We balanced each other out.

DR. WINKLER: Is there a note at all?

CO-CHAIR HOMER: Okay. Good. Did we catch everybody?

DR. WINKLER: Yes.

CO-CHAIR HOMER: Good. Then feasibility.

MEMBER JENKINS: In terms of feasibility this is coming from the national survey and as long as there is still money available to do the national survey, I guess it's feasible to cut the data this way.

DR. WINKLER: I have one question. How often is this survey administered?

MEMBER JENKINS: I think one was every year and the other one was every four years. Did I get that right?

CO-CHAIR HOMER: I'm not sure.

MS. McELVEEN: Yes, we can hear you.
MR. STUMBO: Hi. Okay, sorry.

I've been listening. This is Scott Stumbo. I work with Dr. Bethell. I've been on the call for about a half hour. I just hadn't been able to chime in yet. I wanted you guys to know that I'm here.

This particular survey is currently conducted every four years and it alternates every two years with the national survey of children with cavities.

CO-CHAIR HOMER: Which does make it not ideal from a performance measurement stand. It's kind of hard to track change.

MEMBER LIEBERTHAL: The only thing on feasibility is the inaccuracies. I just think that the data that you are going to get from the parent report is inaccurate, understanding that children with special health care needs may be accurate but I think for healthy children it's inaccurate. I mean, feasibility is being done so I guess that's okay but sometimes garbage in --
CO-CHAIR HOMER: Garbage out?

MEMBER LIEBERTHAL: I didn't say that. I didn't say the second half.

CO-CHAIR HOMER: Okay. So why don't we vote on the feasibility and then we'll vote on the overall measure. How many votes that this completely meets feasibility criteria? I see none.

Marlene.

MEMBER MILLER: No, I wouldn't say completely.

CO-CHAIR HOMER: Okay. Partially?

MEMBER MILLER: Partially.

DR. WINKLER: Fourteen.

CO-CHAIR HOMER: Minimally? One.

Okay. Good. All right. So time to call an overall vote and that's just yes or no, right? That's just recommend or not recommend. So would we recommend moving this forward and endorsing this as a measure? All in favor of recommending the measure. This one is going to be tight
DR. WINKLER: Twelve. Marlene?
MEMBER MILLER: No, I wouldn't.
CO-CHAIR HOMER: Nos?
DR. WINKLER: One here.
CO-CHAIR HOMER: Okay. The measure carries.
MEMBER PARTRIDGE: Could we consider a recommendation? It's not a condition.
CO-CHAIR HOMER: Of course.
MEMBER PARTRIDGE: The discovery that this is a survey every four years is a little daunting and I wonder if we could recommend the measure steward look at the possibility of this data being gathered other than through that survey. In other words, is it feasible to incorporate something else that is done more frequently. It would just be useful to know.
CO-CHAIR HOMER: Sure. Good. That would be great. Okay. That was very productive. Where do we go next?
PARTICIPANT: Thirty-six.

CO-CHAIR HOMER: Another straightforward one. Okay.

MEMBER McINERNY: I just want to answer Lee's question. Certainly school districts report absentee rates to the state. Of course, I don't know why but we don't know exactly why either.

MEMBER PARTRIDGE: Actually, this crosses over into something we haven't talked about much today at all. Where you have these growing health information exchange exercises there are certainly conversations going on about the extent to which some of the data that comes from schools can be shared through that medium. It comes up often in the context of health. That was part of my reason for thinking we might explore more frequently.

CO-CHAIR HOMER: And the process would be if someone came forward with that kind of a measure going forward, then we would go through some harmonization process at NQF.
to choose which was the better strategy to go forward.

Okay. So let's move on to measure 36, children who have no problems obtaining referrals when needed. Could we hear from the committee.

MEMBER LIEBERTHAL: I was on it. You have to define needed versus wanted. Again, this is parent opinion but an example that I put in my comments -- well, if we are just discussing importance, yes, I think it's important that referrals be available, but when we get down to the scientific and usability, I think there are problems again. I'll keep my comments at this point to just yes, it's important.

CO-CHAIR HOMER: Any further discussion since this is important? Good. Are there disparities? Yes, there is a fairly broad range it looks like, 9 percent in Vermont to 29 percent in DC. Okay. Should we have a vote?
MEMBER SCHWALENSTOCKER: Charlie,
I don't know if this comes here or not but I
guess I could use some input on how outcome-y
this is versus process-y and it's a tough one
and I just wonder what your's and other's
thoughts are.

MEMBER JENKINS: This was one of
the ones I was alluding to at the very
beginning with my questions, Charlie, about I
just scored it at face value but you said that
you hit it on the importance criteria.

CO-CHAIR HOMER: Yes, and how
close. I also think this is one that is on
the cusp. It's certainly an outcome of having
an effective system; that is, if you have
referrals readily available but it's not a
health status measure. It's a system
performance measure. Would you consider this
a system outcome measure; that is a reasonable
measure of whether you have an effective
system of mental health?

MEMBER ZIMA: Yes, particularly
for carved-out mental health for kids in Medicaid. It would be an indicator of the need to redesign the system and it will raise a lot of questions about integrating pediatrics and psychiatry together.

CO-CHAIR HOMER: Nancy.

MEMBER FISHER: When you do it that way, what you are really looking at is the kids that aren't getting the referrals. That's what you're interested in. If you say how easy is it to get a referral and so one person gets a referral, you're not worried about that person. You're worried about the 99,000 other ones that didn't get a referral so to me this isn't as important to me as the other side of it because then you get that data and then you have to drill down on it.

CO-CHAIR HOMER: The data that they reported here are 20 percent of children with special health care needs had problems obtaining referrals so that is how they -- the
question is asked in the positive but --

MEMBER FISHER: They are answering it the way that I want the answer.

CO-CHAIR HOMER: Exactly.

MEMBER FISHER: Yes. They are asking one question and answering yet another so that's what I said what --

CO-CHAIR HOMER: It depends. It's actually at the response categories in the instrument.

MEMBER FISHER: You said 20 percent of kids aren't getting it. Right? Is that what you said?

CO-CHAIR HOMER: Yes, children with special health care needs.

MEMBER FISHER: Okay. So 80 percent are getting it.

MEMBER LIEBERTHAL: This is a general -- the denominator is all patients who need referrals whether they have special health care needs or not. The problem with this one in the denominator is how do you
define needing a referral because this is the survey that covers all children.

I believe they asked the same question in the other survey that we tabled but this is of all children. This may be a healthy kid and mom comes in and wants a referral to derm for a mole that a general pediatrician or a wart or something that the primary care provider may not only be perfectly capable of but have additional expertise.

So the mother says, why are you here? I'm here because I want the referral. You say, well, you don't need a referral because I take care of this all the time and do as good a job as a dermatologist. That's where you run into the problem with this one.

CO-CHAIR HOMER: Okay. So let's --

MR. STUMBO: Can I interject here?

CO-CHAIR HOMER: Oh, you certainly may.

MR. STUMBO: Okay. Thank you.
The question does specifically say need.

CO-CHAIR HOMER: Yes.

MR. STUMBO: I think if we're imputing I want from parents which I think is inappropriate.

MEMBER LIEBERTHAL: But you're asking the question of parents so they don't discriminate. If they say I want they mean I need. Since you're asking parents, you're using the parent's decision as to whether they need the referral, not whether they truly need the referral.

CO-CHAIR HOMER: In the index of family centered care and you're talking about -- I mean, that is the value from which NQF operates and six aims of the Institute of Medicine does put family centered care as the prime value.

MEMBER JENKINS: We have to go back to Ellen's question about process versus outcome. I do think that issue about the respondent's bias in the way they might answer
this question is an issue. We could ask perhaps both questions to the measurement developer, to that extent do you believe this is an outcome measure? Then also, do you have any data that would look to the validity of presumption of difficulty obtaining a referral when the question is asked in that very general way?

MR. STUMBO: Someone in our group has written a paper actually looking at the need and the follow up of referrals from the physician's point of view and from the parent point of view and they don't often jive but there are, indeed, cases in which the doctor indicated a need for parent follow up and the reverse is also true related to a worsened outcome. Within the survey itself, again, this is population based health care.

We are able to say that those who were not able to get the referrals they needed, you know, did significantly -- of the child or the rate of the child -- I guess I
would say, and I'm not licensed to talk on the
phone, but I would say it's an intermediate
outcome which is a lack of ability to get a
needed referral clearly has fall outcome.

CO-CHAIR HOMER: So let's go back.
I'm just going to force us back through the
process a little bit. Did we vote on the
importance criteria? We haven't so I would
like to have us vote on whether this meets the
importance criteria which is threshold for
going forward. Does it completely meet the
importance criteria? Just yes or no. Does
this meet importance criteria?

DR. WINKLER: Yes. Marlene?

MEMBER MILLER: Yes.


Okay. All right. So then we need to -- I'm
sorry?

MS. McELVEEN: I was going to say
I still think we need to have a scope vote
because there has been some discussion whether
this is a process or outcome measure which also would --

CO-CHAIR HOMER: I guess -- well, how do we want to -- several of us have felt this is basically an intermediate outcome or a system outcome measure. It's not a health status measure but it is an outcome of having an effect in the delivery system. Therefore, we would consider it under the current deliberations rather than putting it off until July. That would be my suggestion. Should we put that to a vote?

MEMBER PARTRIDGE: Charlie, I want to be sure I'm voting on the right thing here. By saying you had no problem obtaining a referral, I assume what you're talking about is even if the pediatrician said, yes, here's a referral to so and so, you couldn't get in. 

CO-CHAIR HOMER: If you couldn't get in, exactly. You couldn't get approval from your insurance company.

MEMBER PARTRIDGE: It's
essentially if the child needs the services it's not possible to get them or they don't get them.

CO-CHAIR HOMER: Well, again, it's the parent's assessment of how big a problem was it. They said it's either a big problem, a little problem, or no problem. If it's anything other than no problem, it's a problem and it gets scored as a problem.

Tom.

MEMBER McINERNY: Actually, this time I found the question K5Q10. Great. "During the past 12 months did your child need a referral to see any doctors or receive any services?" I would think that would be the denominator and then the numerator is K5Q11, was getting referrals a big problem, a small problem, or not a problem?

There's a bunch of answers; big problem, small problem, not a problem, don't know, refuse. So that could be the numerator. Now, the question is do we lump big and small
problems and say, yes, that's a problem, or do we just say big problems?

MEMBER JENKINS: Numerators have no problems.

MEMBER McINERNY: No problems.

CO-CHAIR HOMER: Right, it's no problem. That's exactly right. Again, I think the question still is are we going to consider this as an outcome measure, enough of an outcome measure that we want to continue with the review at this time. Let me call a vote on that. All those in favor of including it within the outcome measure buckets and continuing the discussion.

DR. WINKLER: Marlene?

MEMBER MILLER: We are voting to call it an outcome measure, yes or no?

DR. WINKLER: Correct.

MEMBER MILLER: I would say no.

DR. WINKLER: Okay. So I got nine.

CO-CHAIR HOMER: So all those
opposed or who said no, it's a process
measure.

DR. WINKLER: Marlene will be five
so it's 10 to five.

CO-CHAIR HOMER: Okay. So let's
continue with the conversation then. Thank
you.

MEMBER McINERNY: Do we have a
representative of the steward on the line?

CO-CHAIR HOMER: Yes.

MEMBER McINERNY: I just have a
question about why this measurement was
structured the way it is and what you think
the potential implications are of putting what
would be not traditionally the enumerator as
the enumerator being no problem and that all
needing referral as the denominator.

I mean, obviously those who have
no problems identifies those who had problems
but is there an advantage of looking at it in
this way or is there some data availability
issue here?
MR. STUMBO: No. I appreciate that question. I was actually going to say something about that. It's funny to think it works this way and I'm now trying to recollect why we defined the measure this way. When we used this, or when others had used this, because this is a measure that does give you quite a bit of literature, we almost always bring that into negative.

We do usually talk about the kid's had a problem. The problem there, as someone on the panel was just asking, there are actually three categories; you had no problem or you had a big or a small problem. We do tend to combine the big and small together.

Basically what we end up with is yes, you had a problem or, no, you didn't have a problem. Why the question was originally not asked that way I don't know. I wasn't around for the origination on that. We do tend to break up the negatives.

I'm sorry that it appears to be
there were -- we are definitely more
interested in the 20 percent who say they have
problems than the ones who don't. Everyone is
reading the denominator properly which is only
if the parent indicated a referral was needed.

MEMBER PERSAUD: In the numerator
details the language to me looks different
than the numerator statement so the numerator
statement is children who need referrals and
have no problems obtaining them. Then the
numerator detail is the numerator describes a
number of children who needed a referral to
see whatever and had problems obtaining those
referrals.

CO-CHAIR HOMER: I think there is
a mistake in the --

MEMBER PERSAUD: Which one of
those things is it and the language should be
the same.

MR. STUMBO: Sorry about that.

MEMBER PERSAUD: So it's had no
problems obtaining them or had? If it's had,
then the first statement has to be changed.

    MEMBER JENKINS: -- is higher scored so I think the way is works is no problems.

    MEMBER PERSAUD: Is no problems so the numerator detail should say had no problems obtaining those referrals.

    MEMBER CLARKE: That's not a big deal. It's like looking at survival versus mortality.

    MEMBER RAO: Just one question for the measure developer. In developing this questionnaire what are examples of small and big problems in getting a referral?

    MR. STUMBO: That's a great question. Again, unfortunately I wasn't around for the development of the actual measure. It doesn't appear to have any -- there is no sort help screen, you know, if the parent asks if it means big or small. It's parent perception and I, unfortunately, don't know what that is based on.
MEMBER JENKINS: Can I ask a follow-up question about the intent? Was this about insurance referrals or did it mean couldn't get an appointment, couldn't get to the appoint? Was it everything about accomplishing the referral? When you chose the word referral did you mean that literal piece of paper that is the insurance referral? To me in the validity part of this question I didn't think that was completely clear. And then, of course, my follow up question did parents really understand it. Before I get that far what was the intent?

MR. STUMBO: I do believe the intent, as someone said earlier, was originally developed for children who need help so that is sort of where it originally comes from. They are using this survey as part of sort of the composite medical whole measure to sort of assist in the performance measure in this regard.
Originally what I think it is trying to effect is for kids who have chronic issues with multiple providers and navigating the system which requires often multiple referrals. To what extent at a population level can we measure that. I'm not sure if I answered your question.

MEMBER PARTRIDGE: By navigating the system so you mean being able to get an appointment or having somebody help you get an appointment? We have system navigators and we have just plain access problems. I can tell you there are no child psychiatrists in southern Texas or something like that. Which are we talking about?

MR. STUMBO: The intent was access.

MEMBER LIEBERTHAL: Taking the wording literally it's whatever the parent perceives with the outcome seeing the specialist who they were referred to. What they went through and what the system went
through to get them there is immaterial to the parent.

If you take this literally, it's what they perceive as the problem. If they want the referral and the PCP says, oh, no, you don't need a referral. That presents a problem. If the system makes it difficult for the PCP to fill out the paper or the insurance company refuses it or there is no access or there are no providers, those are all problems and it's what the parent perceives. Am I reading that correctly?

MR. STUMBO: I would agree with that. You would not necessarily be able with these two items to discern the difference between those two.

CO-CHAIR HOMER: I think the analogy here is the measure we just had on school days. In other words, this is kind of a global outcome. There could be a variety.

I think the lineage of this question is old enough that it probably was
during the heyday of gate keeping when the
issue may have been issues around is your
doctor going to actually write the referral.
Now it could be more about shortage of
pediatric subspecialists or access to mental
health or Medicaid restrictions and benefit
levels and things like that, payment levels.

MEMBER LIEBERTHAL: Or the child
may be -- everything may go smoothly and they
may get to the specialist and the specialist
is an adult specialist who knows squat about
children.

CO-CHAIR HOMER: This really is
just kind of a yellow flag that says there's
a problem and one would need more detailed
measurement to find out what it is.

DR. WINKLER: Charlie, based on
this question and the previous discussion, it
sounds like one of our gaps we might want to
explore in some detail is while these present
global issues, there is a desire for having
measures that are a little bit more targeted
to answer the questions why that could be
looked at the provider level or plan level or
system level or something that would be a
little more specific to understanding what all
the inputs are that this global measure
reflects.

CO-CHAIR HOMER: I think that's
great.

DR. WINKLER: Okay. That's a gap.

CO-CHAIR HOMER: Okay. So are we
at a place where we can vote on the scientific
acceptability that specifications,
reliability, validity, exclusions, risk
adjustment, etc., meaningful differences,
comparability, and disparities?

PARTICIPANT: Sure.

CO-CHAIR HOMER: Sure. I think
we're wearing them down. So I'll say to what
extent does this completely meet the criteria
for scientific acceptability? I see none. To
what extent does this partially meet?

DR. WINKLER: Marlene.
MEMBER MILLER: Yes, I'll say partially.

DR. WINKLER: Okay.

CO-CHAIR HOMER: And then minimally. We have two.

DR. WINKLER: Marlene, I didn't mean to railroad you.

CO-CHAIR HOMER: Okay. So do we have everybody then?

DR. WINKLER: Yes.


DR. WINKLER: Except which might be embedded in something like CAHPS or some of the other survey pools.

CO-CHAIR HOMER: Does CAHPS -- do we know if CAHPS has anything on --

DR. WINKLER: It's not just CAHPS actually around children because there are
several other survey instruments and I can't
remember the questions on them now.

CO-CHAIR HOMER: Is this in the
group CAHPS?

DR. WINKLER: Well, there is the
clinician group CAHPS. Remember we have also
done several others that are focused around
adolescents, YAHCS, and I forget the other
one.

CO-CHAIR HOMER: I don't think
it's in YAHCS or PHDS but I do think it might
be in CAHPS.

Kathy?

MEMBER JENKINS: It would
certainly be the --

CO-CHAIR HOMER: Yes, supplement.

DR. WINKLER: The pediatric module
with the chronic? Yes, and we've endorsed
that one, too.

MEMBER JENKINS: I was going to
ask the measure developer about usability.

MR. STUMBO: I actually don't
know. I'm sorry. I don't recall.

CO-CHAIR HOMER: You're living
with the illness survey basically. I think
maybe that's a note to both the developer and
also to --

MEMBER JENKINS: Charlie, I will
say that this measure, and then the next one
we're going to discuss, is around effective
care coordination coming out of this group.
I think both of these in my mind are speaking
towards the new initiatives around development
of medical home. To that extent they are very
important nationally.

CO-CHAIR HOMER: I am struck on
the understandability. On one hand it sort of
makes sense that you have problems or not but
just the debt of conversation around the room
suggested that this group, at least, maybe
because we have such a glandular knowledge of
the health system had a hard time really
understanding what having a problem with the
referral meant.
So if I were reporting to the public that whether they would share that or whether they would get it, I do have a little concern given how much trouble we had as a group getting our head around what this exactly meant. Okay.

Why don't we call for a vote. How many feel this completely meets the usability criteria? Zero.

Marlene?

MEMBER MILLER: No.

CO-CHAIR HOMER: No. Okay. How many this partially meets the usability criteria?

DR. WINKLER: Ten.

CO-CHAIR HOMER: How many feel it minimally meets the usability criteria?

DR. WINKLER: Four. Marlene?

MEMBER MILLER: I'm a no.

CO-CHAIR HOMER: Okay. Did that get everyone?

DR. WINKLER: That's it.
CO-CHAIR HOMER: All right. The last one is the feasibility. I guess this probably is going to echo the last one which comes from the survey which happens only every four years. How many feel this is completely feasible? How many feel this is partially feasible?

DR. WINKLER: Nine.

CO-CHAIR HOMER: And how many feel this is minimally?

MEMBER MILLER: I'll vote partial.

DR. WINKLER: Okay. Thanks.

CO-CHAIR HOMER: Now the global recommendation. Do we recommend this measure to go forward for approval or not? All those in favor -- oh, please.

MEMBER CLARKE: I think we absolutely need to stipulate that there is no way it can go forward without resolution of which way are they going to look at it and have it consistent throughout the application.

CO-CHAIR HOMER: And clean up the
specification.

MEMBER CLARKE: It has to be changed no matter what the outcome of this vote is.

DR. WINKLER: Right. Yes.

CO-CHAIR HOMER: Very good. So assuming, again, which I think is pretty technical, pretty straightforward, that they are just not consistent in the definitions throughout.

So all those in favor of approving this or recommending it move forward for endorsement to be precise. Okay.

Marlene, did you vote one way or the other?

CO-CHAIR HOMER: All those opposed?

DR. WINKLER: Marlene?

MEMBER MILLER: That was a no.

CO-CHAIR HOMER: That's a tough one.

DR. WINKLER: Nine to six. It's
still yes.

CO-CHAIR HOMER: It's still yes.

All right. Any strong arguments for reconsideration? I guess not. We can reflect on it overnight and if people have second thoughts, we can discuss it tomorrow.

MS. McELVEEN: So we can take a short break if you'd like for about 10 minutes and reconvene and wrap up three more measures for the rest of the day. Is that okay with everyone?

CO-CHAIR HOMER: I think we're doing great. Terrific. Thank you.

(Whereupon, the above-entitled matter went off the record at 3:08 p.m. and resumed at 3:23 p.m.)

CO-CHAIR HOMER: Why don't we get started. If we could reconvene. I just want to get started.

MEMBER McINERNY: Some of you may realize, may or may not realize, but the American Family of Pediatric Legislative
Office is two floors below. I popped down and
Bob Hall from there said he wanted to come up.
Bob was single handedly the person who got
health care reform passed.

CO-CHAIR HOMER: I would say it
was Marina and Bob together.

MEMBER McINERNY: Marina and Bob.

CO-CHAIR WEISS: I don't think so.

I'll give him credit.

MEMBER McINERNY: And, of course,
the AAP Legislative Office will be watching
closely what happens and making sure that some
of the very important things for children that
had been promised will actually take place.
He's very interested in this process and was
happy to hear that it looks like we are going
to be looking to CHIPRA measures as well. He
just wanted to say hello to everybody.

CO-CHAIR HOMER: Thanks for coming
up. It's a public meeting. You can make
public comments.

MS. McELVEEN: Alright. Moving
along with the CAHMI survey measures. We are onto the next one. We are on measure No. 38. The title of this measure is Children who receive effective care coordination of health care services when needed.

This is a composite measure used to assess the need and receipt of care coordination services for children who required care from at least two types of health care services which may require communication between the health care providers or with others involved in the child's care.

We will get started with importance.

MEMBER JENKINS: I don't know if you want to say anything, Allan.

MEMBER LIEBERTHAL: Kathy, why don't you start.

MEMBER JENKINS: In terms of importance, I think similar to the last measure that we looked at this is coming from
the National Survey of Children's Health and
is clearly square in the national conversation
about medical home and coordination of care.

    What the measure is doing, I
think, as we've just heard, is attempting to
use a composite of answers from the National
Survey of Children's Health to assess
effective care coordination.

    I don't know if people can
understand the importance without knowing just
a little bit more about the enumerator and the
denominator so I think I'll just say something
about that and then I have a question for the
measurement developer.

    This one is a little bit more
complicated than the others in that the
enumerator -- let me start with the
denominator which is a little simpler.

    The denominator are all
respondents did a survey of children zero to
17 years who needed care coordination and
needed care coordination is defined as needing
two or more of the following services; a personal doctor or nurse, a mental health professional, a specialist, or the child's doctor felt that the child needed to see a specialist. All the children who meet those criteria are the denominator.

The numerator is a composite and the and/or's are a little confusing to me so I think I might ask the measurement developer to clarify them. Parent report. Someone helping to arrange or coordinate child care among the different doctors and services.

And then, and I think this is an "and" statement, either the parent reports they have not felt they could have used extra help arranging or coordinating child's care among the different health care providers or services, or the parent reports that they have felt they could have used help and they got as much help as they wanted with arranging or coordinating the child's care.

Then I think it's an "and"
statement, the parent reports satisfaction with communication among doctors or other providers. It's a little bit confusing and I think what their intent is to ask for when the parent thought there was a need and then that they thought the need was fulfilled.

It was a little confusing to me in terms of parent report someone helping to arrange without the criteria about whether or not the family was satisfied. It's a hard sentence to say so I'm not sure if everyone followed that. If we could ask the measurement developer to help clarify the and and the or's in the numerator statement, I think that would be helpful.

MR. STUMBO: Sure. I would be happy to do that. Let me first say I think it would be better to think of me as the steward of the steward rather than the measure developer.

MEMBER JENKINS: I'm sorry. I misspoke.
MR. STUMBO: All these items were developed by the expert panel for the Paternal Child Health Bureau to do both of the national surveys. There were 15 experts across field who came up with these items. That being said, I will do my best to explain and I have actually worked quite a bit with the data. Actually there might be a slightly simpler way. I could discard the denominator and I think it's best to take the denominator at the moment as all children under 17 who use two or more of those technical services that you were describing. There was one that got left off in our office but it's online.

The mission is dental care as well. Presumably any child who has used two or more services, has a primary care physician, special care, and mental health professional care are potentially are eligible for some sort of care coordination services.

MEMBER JENKINS: So the survey distinguishes between used the services versus
needed the services. Is that correct?

MR. STUMBO: That's correct. The actual count is the use of those services. For instance, if the child went to their primary care physician during the past 12 months but did not see a mental health professional specialist, or even a dentist they would not be the denominator. If someone went to their primary care physician and dentist they could actually be the denominator. They are the denominator I should say.

If I can just go ahead, the numerator I think I can maybe make it a little clearer. I'm hoping I can. Really there are two ways of getting into the numerator. I very much understand the confusion.

This is something that we worked on quite a bit with the National Health Statistics, Paternal Child Health Bureau and numerous Title 5 groups across the country who really understand the care coordination.
component because it's not captured elsewhere and we believe this is at least a good turning point although it's probably not the perfect measure.

To get into the numerator you could either have fed directly to a series of questions that someone did indeed help arrange care for you based on the fact that you had two or more services. Following on that you either said you got all the help you needed or you didn't.

If you said you didn't, then you actually did not receive enough care coordination which you would not be the numerator of the care coordination. You can ask me questions if that's not clear.

The second way of getting into the numerator because the technical expert panel determined that term in and of itself often does not make sense to parents. Anyone who used two or more services and reported that they were highly satisfied with the
communication between their doctors also could be refused care coordination.

It's possible to say, "No, I did not get any help." The thinking from the technical expert panel is that often parents (a) don't know what that means and (b) don't seem to know that they need help or that they could get help. If they had multiple service use and reported that they were highly satisfied with the communication among providers, that also qualified them for care coordination.

MEMBER JENKINS: There is a series of "or" statements. Any of the above makes you eligible for the numerator?

MR. STUMBO: That could be correct. Right. You could have gotten care coordination and --

MEMBER JENKINS: I thought they were "and" statements.

MR. STUMBO: Okay. I'm going to look at this while you guys discuss the other
thing.

MEMBER LIEBERTHAL: I didn't get into the wording as carefully but overall I actually liked this measure for all of the rating factors because it really comes down to whether the parent was satisfied or not and that is really the outcome you're looking for, parent satisfaction. With that as the outcome, I thought it was a good measure.

MEMBER McINERNY: Would it be helpful -- again, I found these exact questions. Would it be helpful to read them, Charlie?

CO-CHAIR HOMER: Yes, fine.

MEMBER McINERNY: "During the past 12 months have you felt that you could have used extra help arranging or coordinating your child's care among the different health care provider or services? Yes or no."

"During the past 12 months how often did you get as much help as you wanted with arranging or coordinating the care?"
Never, sometimes, usually."

Then, "Overall were you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among the child's doctor and other health care providers? Very satisfied, somewhat satisfied, somewhat dissatisfied, very dissatisfied." Then there's a thing, "No communication needed or wanted."

When you start to try and put all those together it gets a little confusing.

MEMBER PERSAUD: So the question is which of those responses, what combination of those constitute the numerator patient perceived got coordinated care. Is that right?

MEMBER JENKINS: That's the question I was asking the measurement developer. Then if we have clarity about that, I guess we can vote on importance.

MR. STUMBO: Let me take the negative numerator first because I think it's
a little bit easier to explain. There are
ands and or's when you get into the positive
numerator. Did not qualify as having
effective care you did not get all the help
you needed for care coordination, or you were
not satisfied with the care of one provider.

MEMBER JENKINS: You mean with the
patient?

MR. STUMBO: Yes. To get into the
numerator you basically had to have received
all the care coordination you thought you
needed and been happy with communication
between providers and been happy. The third
one kind of relates to the second one which is
if communication is needed between provider
and school, coordinated care with school.
Again, it's a satisfied or not satisfied
question.

If you felt you got all the care
coordination that you needed, and you were
happy with the communication among providers
and happy with the communication between
providers and the school, then you had care coordination but there is "and" between each of those three things.

Now, there are lots of legitimate skips out of all these questions. If you did not need care coordination or didn't need communication, you can still get into the numerator. You were just legitimately out of that component of the measure.

MEMBER LIEBERTHAL: So for your numerator if the parent reports satisfaction with communication among doctors or other providers, if the parent answers yes that they were satisfied, do any of the other bullet points mean anything?

MR. STUMBO: Well, you do have to have all three components and so if you are satisfied with the communication, that you reported you did not get all the care coordination help that you needed, you would not be in the numerator so it is not helpful to qualify just by saying you were happy with
the way your doctor and dentist talked to each other.

You could have said you didn't need any care coordination help. This may or may not be clear. It's a huge tree diagram that we try to diagram it out for people. You could literally say you didn't get any care coordination help and didn't need any because you either didn't know you needed any and said you were satisfied with the communication between all your providers in which case you would be a numerator.

You could not qualify as a numerator if you said you needed help and didn't get it but were satisfied with communication between your providers.

MEMBER LIEBERTHAL: It's getting more confusing.

CO-CHAIR HOMER: So let's ask the first question. To the extent we understand what this measure is measuring is it important. We know the concept of
coordination is very important but I guess the
next question is as measured is this something
-- is it measuring something that's important?
Do we have indication that this is a big
problem or that there is meaningful variation
across sites? There's a gap in performance?

MEMBER JENKINS: The application
does show variation with various levels of
other responses in the survey like they have
for other measures coming out of the survey
which is a little different but I do think
they are trained to measure a construct that
there is no gold standard for.

CO-CHAIR HOMER: So let me just
again just to sort of push the process forward
a little bit, it seems like why don't we vote
then on importance. It sounds like it does
meet those criteria but that is a threshold
question, yes or no.

Is this measure sufficiently
important that we want to go through and
consider whether it's actually scientifically
credible and useful and feasible and all that
other good stuff. All who believe it is
sufficiently important raise your hand. That
looks pretty universal.

DR. WINKLER: Marlene, are you
still there?

MEMBER SCHWALENSTOCKER: I think
she may have had to get off.

DR. WINKLER: Okay.

CO-CHAIR HOMER: Marina is out for
a minute.

DR. WINKLER: We'll vote her
proxy.

CO-CHAIR HOMER: Okay. All right.

Then let's look at the scientific
acceptability dimension and see how we are
feeling about those elements again.

DR. WINKLER: Just one thing to
ask the measure developer. You mentioned that
you drew out a tree diagram. Is that
something you could share with us?

MR. STUMBO: Yes, certainly.
DR. WINKLER: Super. For anybody who is going to view this measure going forward that would be very, very helpful. We may not have it right now but I think that is something we do need.

MEMBER ZIMA: Just one more question. You had mentioned schools but I noticed in the denominator it says health services. Are you thinking services broadly or within just health care?

MR. STUMBO: Yes. That's a good question. Right. These are health services broadly. For instance, there was a mental health or emotional behavioral issue which went through IDT at school it required communication between the school and any number of providers. That's what it's referring to.

MEMBER ZIMA: Would it go so far as foster care to put a kid on a home placement risk?

MR. STUMBO: No, the question is
very specific; does your child require
communication between any of the providers and
the school.

CO-CHAIR HOMER: So parental
judgment. If the foster parent felt that was
important, they could say yes. It's parental
judgment about whether they think that there
needs to be communication between that health
care provider and the school.

Tom.

MEMBER McINERNY: Yes. Would this
include therapists such as physical
therapists, occupational therapists, speech
therapists also?

MR. STUMBO: That's correct.

MEMBER McINERNY: Okay.

MEMBER LIEBERTHAL: Getting back
to that last line, parent reports
satisfaction. It would seem to me that if the
responses were negative on the previous three,
then the parent would not be satisfied with
communication.
If the answers were positive to all three, the parent would be satisfied. Since we are really dealing with parent satisfaction, I think this would have been much simpler had you only asked the fourth question or the measure was only based on the fourth question and that's whether they were satisfied or not.

CO-CHAIR HOMER: Okay. At this point, again, we have a measure before us. I guess we could recommend they revise it.

MEMBER LIEBERTHAL: Yes, that's what I'm getting at is that we could recommend that. It depends on how we choose to interpret those four questions.

CO-CHAIR HOMER: So you're suggesting that you would prefer something that simply looks at parent reported satisfaction with communication among doctors?

MEMBER LIEBERTHAL: I see this as a patient satisfaction issue and whether the doctors and the other providers thought they
had communicated. If they hadn't conveyed it to the parent and the parent wasn't satisfied with the communication, then the system failed the parent.

CO-CHAIR HOMER: But communication and coordination are not the same.

MEMBER RAO: I thought it was the issue of our they satisfied with the coordination itself, not the actual communication.

MEMBER JENKINS: It's actually both. There is another statement of the algorithm under 2(a).21.

MEMBER RAO: Right. That's what I was looking at.

MEMBER JENKINS: After the beginning with the ands and the ors it says, "Parent reports that they got as much help as they wanted with arranging or coordinating care." That's a parent satisfaction report.

Then there is also in addition parent report satisfaction with communication
with doctors when needed and further
satisfaction with communication between
doctors and others involved, e.g., schools.

Back to Allan's point, if you just
combine those last three without the beginning
part, you would have a pure composite parent
satisfaction report on both care,
coordination, and communication among
providers and with schools.

It will also solve one of my other
validity issues which had to do with would the
family necessarily know and identify that
someone had helped coordinate care or who that
was. I think a lot happens behind the scenes
sometimes that parents are oblivious to.

MEMBER PARTRIDGE: I did
understand this to mean that they were
measuring two separate dimensions. What I
would call the case management kind of aspect,
somebody who facilitates getting records
forward and helps you make the appointment and
identifies the proper specialist, etc., which
is one function.

And then there's another dimension we're looking at and that is the dimension around my child saw the specialist. Did everybody talk to everybody else and did I think it all worked out well. That's the communication and coordination of care aspect. Those are two distinct things in my mind.

I think Allan is suggesting that we drop the first. Am I right? You're saying that you're satisfied with -- it doesn't say did you have trouble getting to the specialist in the first place. We aren't asking about that anymore.

MEMBER LIEBERTHAL: I'm suggesting that it be simplified into one, that the numerator have one statement whether it is a composite statement that includes the others but it not be ands and ors.

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

When we ask directly did someone help coordinate your care, what they have found among the children with special health care need in the community is that people don't know that's available. They don't really know what it is. The communication needs to be added in to try to cast a slightly wider net. I might agree that these are two slightly different things now.

CO-CHAIR HOMER: So I think this is influencing at least my judgment on scientific acceptability of the measure. I don't know what other people are thinking. Also as I'm thinking of this if you look through the elements here it seems like it's well specified but if it took us 45 minutes to kind of understand those specifications, I guess sometimes things need to be complicated. Just because it's hard doesn't mean it's wrong but maybe it's either not sufficiently clear
or --

DR. WINKLER: I think one of the issues is always conveying the information. I think some of the measures we see with complex risk adjustment methodologies can be quite dauntingly complex to grasp all of the details. To the degree that we can explain it in a straightforward fashion as possible for a wide audience will be important.

I think if a tree diagram explains the numerator better than a series of statements that you get lost in, let's go with the tree and whatever works to communicate how the measure is constructed most effectively.

CO-CHAIR HOMER: There also sounds like there are some meaningful questions about the validity of this measure because it is taking two different constructs, one being this coordination facilitation which we are not sure parents can record on accurately. Then we've got this thing on satisfaction with communication which is easier to understand
but not necessarily the same construct.

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

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

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

DR. WINKLER: Okay.

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

DR. WINKLER: That might be helpful, too.

MEMBER JENKINS: I guess what I'm
hearing is that it's a very important construct. There is certainly part of it here. It feels a little underdeveloped to me. I mean, at the end of it what I would love to see is however it's measured in the survey that it sort is evaluated in terms of its validity with something else that is reflective of care coordination.

I'm just not seeing that quite yet here. That doesn't mean that descriptively looking at the measure this way might not be interesting and it might not be valid as written. I'm just not sure that I can see that right now.

CO-CHAIR HOMER: So I guess the question is do we have enough information that we should continue with the voting or do we need to look at some more background materials? My inclination is we probably have enough but I don't know. What does the committee think? Do we want to get more materials from CAHMI or do we want to sort of
proceed?

The importance we voted on. We're really talking about scientific acceptability. That's where we were right now. I think some people are not even certain about the validity. Are they measuring, what are they really measuring, what evidence do they have, does this correlate with other indicators of good coordination if there are any.

MEMBER CLARKE: I get the impression that the committee doesn't really understand it that well right now. There's not sufficient detail in that. We need the tree.

CO-CHAIR HOMER: So should we table this then and ask for the tree and some other data before --

MEMBER JENKINS: Maybe we could go through the process and we could end up with one of those to be avoided recommendations with conditions or something. I'm back to Allan's point that he liked a lot of it.
CO-CHAIR HOMER: Why don't we do the voting then on the scientific acceptability. How many feel this completely fulfills the acceptability criteria? I see none. How many feel it partially meets the scientific acceptability criteria?

DR. WINKLER: Four. Okay.

CO-CHAIR HOMER: And how many feel it minimally meets the criteria?

DR. WINKLER: Marlene? She's gone.

CO-CHAIR HOMER: Did we get everybody?

DR. WINKLER: Marina and Marlene are gone so now there are 13.

CO-CHAIR HOMER: Okay. Usability. That is how understandable this is. Is it harmonized with other measures and does it provide added value. We've had a long discussion about understandability and harmonization. Again, there may be some indicators in CAHPS that gets vaguely at this
issue of communication so we are going to need to talk about the added value of this compared to the CAHPS measure.

MEMBER PARTRIDGE: Right. I was going to ask if we could -- I'm pretty sure that HCAHPS, the health plan, not hospital CAHPS.

CO-CHAIR HOMER: The original.

MEMBER PARTRIDGE: Health plan CAHPS has some questions of the beneficiary, of the member, about care coordination.

MEMBER ZIMA: And I believe the consumer measures got four items or so specifically asking whether the doctor listened to and understood and appreciated their cultural values and things like that.

CO-CHAIR HOMER: Yes, but that doesn't necessarily deal with the issue of communication with other providers which this is at and coordination amongst multiple sectors. This is more about --

DR. WINKLER: We can pull the
1 survey tonight.

 MEMBER PARTRIDGE: I've been reading it so much the last two weeks you would think I'd have it engraved in my head but I'm almost certain there are very similar questions in it.

 CO-CHAIR HOMER: My recollection was they tried and that they really had a hard time with these. That was when I was a developer which was a long time ago.

 Okay. So votes then on the usability. How many feel this completely meets the usability criteria? I see none. How many feels this partially meets the usability criteria? I see two. How many feel this minimally meets the usability criteria? I see a bunch.

 Now the feasibility criteria, data by product of care, electronic, exclusions, inaccuracies, and implementation. Again, this is the survey, another survey, two per year.

 MEMBER JENKINS: I think the only
issue here is the fact there are inaccuracies
based on interpretability to the respondent.

CO-CHAIR HOMER: So how many feel
this completely meets the feasibility
criteria? How many feel this partially --
right? Isn't that the next one? Okay,
partially. Minimally? All right. Now a
global vote on: do we want to recommend this
go forward? Again, there are
different ways we can recommend to go forward.
We can recommend it go forward as endorsement.
We can recommend a conditional endorsement,
that is, with criteria for some modification
or testing or clarification, a time-limited --

DR. WINKLER: This really wouldn't
be.

CO-CHAIR HOMER: This wouldn't be?

DR. WINKLER: No. It's been
tested. Time-limited is available for
measures that have never been tested.

CO-CHAIR HOMER: So this is either
endorsed or recommend for revision and
clarification, to give us more information and come back.

MEMBER JENKINS: We've recommended with conditions before.

CO-CHAIR HOMER: Okay.

MEMBER LIEBERTHAL: When you say this has been used, has it been used in this form, or the individual questions have been used?

CO-CHAIR HOMER: I mean, this aggregate -- again, you can go to the website and find out how your state does compared to another state, so that is the use in that context.

MEMBER JENKINS: In the composite? I don't think that's right. I thought it was just in the individual component.

CO-CHAIR HOMER: No. You can go on the composite. You can compare right now, for example, children who did or didn't need. You can compare it by state -- again, nationally, it says 58 percent did not need.
care coordination; 28 percent received all the
care coordination they needed; and 12.9
percent did not receive care coordination as
needed which is the --

 MEMBER LIEBERTHAL: But those are
different.

 MEMBER JENKINS: Those are
questions.

 MEMBER LIEBERTHAL: Those are the
individual questions, not the composite.

 MEMBER JENKINS: Not the
composite. That was my understanding, is that
the composite was new.

 MR. STUMBO: It's there. It is
there.

 CO-CHAIR HOMER: The composite
using this --

 MR. STUMBO: In addition to all
the individual items, so you can see sort of
how many said yes or no to each of the six
items total.

 CO-CHAIR HOMER: Yes, I mean, the
question I just gave says it's from question 22, 24, 30, 31, 32, etc. It's a component of the medical home composite. Isn't it?

MR. STUMBO: That is correct.

CO-CHAIR HOMER: So it is widely reported and actually fairly widely published.

Okay.

MEMBER LIEBERTHAL: Before we vote, can I ask you a question then?

CO-CHAIR HOMER: Sure.

MEMBER LIEBERTHAL: If they are using it widely in the format it's in, is there any point in our either recommending with conditions, versus not recommending?

CO-CHAIR HOMER: Again, the reason that it would be important for NQF either to recommend or not is the use in Medicaid and by CMS.

MEMBER LIEBERTHAL: I'm not saying recommending or not recommending, but having the third alternative -- meaning with conditions. Seeing that they are already
using it in its current form, is there any point in our asking for conditions?

CO-CHAIR HOMER: Yes, because if we recommend it, if the group is fine, then we can go ahead. If we don't recommend it, then it's not going to be eligible for use in these variety of contexts. If we recommend it with conditions, then they could modify it and it could still be then used in another testing. Is that right?

DR. WINKLER: I'll split the difference with you. The fact is, you can make the conditions, but it's a no vote unless they do make the changes. For a measure that is well established and well in use, you know, the likelihood of rapid modifications doesn't seem very great. I would be more than happy if the measure developer would jump in and respond as well.

MR. STUMBO: I'm sorry. I missed the last question. I apologize. What was the question?
DR. WINKLER: The committee members have had some recommendations on the various components of the measures, and if they were to recommend this measure with -- conditioned on adjusting the measure somewhat, how likely would it be that would even be possible from the measure developer's perspective?

MR. STUMBO: From the discussion I've understood so far, it would be possible for us to calculate two different -- kind of separate out those two components we were talking about, which is the more direct measure of care coordination versus communication satisfaction among service providers, and that is feasible. It's not currently how we think about it, but it is something we've talked about doing, given the items that are surveyed.

MEMBER PARTRIDGE: And am I right, that this is one of the components of the big survey that is administered once every four
MR. STUMBO: Correct. It's actually every two years from the fact that the exact same measure is included in the national survey for children with special health care needs.

MEMBER PARTRIDGE: Right.

MR. STUMBO: So every two years these exact same items are being asked, either of all children or children with special health care needs.

CO-CHAIR HOMER: So if we were to put conditions, what would the conditions be that we would like to add, before calling for a vote?

MEMBER PARTRIDGE: I would be interested in seeing it coming back as two separate measures.

MEMBER RAO: One for satisfaction and one for coordination.

CO-CHAIR HOMER: So I see that then that we're tabling it, or we are not
approving it as is, and inviting them to come
back rather than approving with conditions.

MEMBER JENKINS: I need
clarification about what it is, and then my
question is not about use but about
validation, in terms of what it means. If I
understood the algorithm better and it had
been validated, then it may be approvable in
my mind the way it's written. I just can't
get clarity around that. I understand it's
being used. It's in the survey and there are
answers within the survey, but to me that is
very different than being validated for any
external standard. That's where I'm not
understanding if it's in one concept or two.

CO-CHAIR HOMER: So, Reva, what is
your sense then of what would be better here?
My sense is if we were to just vote it up or
down as it is now, probably people -- my guess
is we're not going to approve it, but there
seems to be interest, and some of that is
based on not being able to understand it as it
is and wanting to see more analyses.

    DR. WINKLER: I think that one

option is that you could say that you just
don't have enough understanding of the measure
at this point to vote on it. And perhaps with
the additional information that we've
discussed with the measure developer -- the
tree, any publications, things like that --
perhaps that would be the sufficient
information you would need, and then you can
go ahead and make a judgment. I'm seeing
nodding heads.

    CO-CHAIR HOMER: I think so. I

was in a side bar. I'm sorry. I was being
bad.

    DR. WINKLER: I know you were in a

side bar.

    CO-CHAIR HOMER: You solved the

problem. This is it.

    DR. WINKLER: They all decided

they prefer not to vote until they have the
additional information.
CO-CHAIR HOMER: That's good.

MEMBER JENKINS: For that last point, please bring the information about the individual components, because we are hearing a call for that information.

CO-CHAIR HOMER: Individual components, the coordination and the communication as two separate items. We want separate and together, and we want to see the algorithm as well.

DR. WINKLER: Tomorrow?

CO-CHAIR HOMER: Well, tomorrow if they have them. The other would be if there is any validation data that cross-matches this with any concurrent kinds of information. If it's been used in programs, for example, where they have online communication between providers -- do you see different kinds of responses in the survey or something like that.

DR. WINKLER: Charlie, let's ask the measure developer. Is any of that
information something you could email to us now or this evening so, that we can share them?

MR. STUMBO: I can try.

DR. WINKLER: Okay. We'll be looking for it and we'll share it with the committee as soon as we see it. Thank you.

MS. McELVEEN: All right. Moving on to the next measure. It's Measure 39. The title is "Children who live in communities perceived as safe." This measure ascertains: Do parents perceive safety as the child's community or neighborhood? Comments and then discussion.

MEMBER LIEBERTHAL: This was, again, Group 3. They don't define the word "safe." Depending on who you are, where you live, safety can have a very different meanings. It's important to know if communities are safe but again -- very similar to others -- we are dealing with patient perceptions, and without more understanding of
what is meant by safe, I don't know how people
would respond to it.

MEMBER DOCHERTY: Family A or
family B -- you know -- have different
definitions of what safe is, in whatever way
they define that to be.

MEMBER LIEBERTHAL: The problem I
have is, again, if we're trying -- this is
solely for calculations. It depends on how
you analyze it. In Los Angeles parents who
live in South Central may consider safety that
they can go a month without a drive-by
shooting, whereas a family in the suburb think
the neighborhood isn't safe unless they can
walk unaccompanied down the street at night at
2:00 in the morning without fear of being
splashed by a car going through a puddle.
Very different worlds. In this case, I don't
accept the perception of safety as being true
safety.

MEMBER JENKINS: I also was in
group 3, and I struggled exactly over this
dynamic and came down, I think, a little bit to the idea that perception of safety is probably an outcome measure all by itself, regardless of safety for sure are defined differently.

I then struggled a little bit about scope for the committee and this work. It was fairly far from sort of health outcomes, so I know we did cast a very broad population-based net, and this was sort of pushing my boundaries there.

Then we have the whole issue of the survey methodology and all the rest of it, so I was really curious what other people on the committee thought about scope for this question.

MEMBER RAO: I just want to point out -- the questions themselves are actually frequency-type questions; how often does your child feel unsafe or safe in their neighborhood. They are not about how do you perceive the neighborhood in general. I think
that makes it a little better indicator.

MEMBER FISHER: I do see how this relates to health, because if you perceive yourself as not being safe, that's a stressor. And then the other thing is if it's not safe and you are trying to keep your child from danger, like you said, drive-by shootings, and you stay in the house and you sit in front of the TV more and you play video games more and you put on more weight and you don't do things that keep you quite as healthy. So I do see this as, what do you call it, one of the social determinants of health and a very important one.

I do understand what they are saying about the perception, so it may be that if you took this and you got people's perception, maybe the comparison would be some national standard that says whether it's safe or not. But, you know, it depends on how you look at it. But it's important.

It's the same thing as, you know,
if your doctor comes in and asks you on a scale of one to 10 what your pain is, and they are trying to find out, they need to ask you what is the worst pain you felt, because the worst pain you felt may have been being hit by a car, versus someone who fell down the stairs. I understand the problem with that, but if you're just trying to sort of give how it affects people and their perception and maybe the quality improvement, then you don't want to put out the people that are not safe. I don't know.

CO-CHAIR HOMER: I want to reinforce, I think, both of your comments. I think it was a great question, Kathy, in terms of business and scope, but I do think you pointed out the exact two reasons that it is. The whole life course work on the impact of stress and now the static load and all the jargon that our colleagues talk about.

This definitely relates, and it's not exactly the same the other indices of
stress. Safety has its own slightly unique
dimension to some of the other areas, so I
think from that perspective as well as the
physical activity one it makes sense.

Again, Allan, to your point -- it
isn't precise and it varies, that's true. To
my point that's not the same as SES, which is
ture but it certainly correlates. Again,
while we are talking I looked it up. For
parents who report their child is never safe --
using the frequency -- if you are less than
the poverty level: 6 percent, 5.9 percent.

If you are 100 to 200 percent, 3
percent. It's not quite monotonic because the
200 to 300 percent is 1.7 percent, and 400
percent or more is 0.8 percent. So if you are
less than 100 percent of poverty, 6 percent
say you're never safe, and if you are over 400
percent less than 1 percent say never safe.

So it's not perfect, so obviously
there are some people in wealthy neighborhoods
or who are wealthy report that, but the odds
ratio is six. The relative risk is six, and that's a pretty powerful effect.

MEMBER LIEBERTHAL: When I was looking at this, I wasn't thinking in terms of looking at subsets of the population. I was looking at it as an evaluation of the overall population. So if you are looking at subsets as you just reported, then it makes a lot more sense to me.

CO-CHAIR HOMER: I used that more as a psychologist, you know, it's really just a validation. You would predict that feeling unsafe would be correlated with poverty, and it is in a pretty strong way, so it's really just an indicator that it's not -- even though there is individual variability on perception of safety, this at least provides some concurrent or convergent validity.

MEMBER LIEBERTHAL: But in response to my issue of improving quality -- because now you could say if you are below the poverty level and last year six percent felt
safe and next year 15 percent felt safe --
then you've had improvement.

MEMBER RAO: I just want to get
back to the issue of frequency, and I think of
safety more broadly. One of the things is
bullying, which is a big issue. That wouldn't
necessarily be neighborhood-dependent. It's
how often your particular child is bullied.

CO-CHAIR HOMER: Which is a very
good point.

MEMBER FISHER: You know, the
other thing is that I know that we say safety
is a matter of poverty, but I'm beginning to
think that's changing. We need to measure it
over time.

I mean, the thing I was thinking
about is the more time you spend inside and
the more time you play those video games, the
more desensitized you get to reality and guns
and what they do, and then we see this in
schools that you would not consider poor
neighborhoods. To me I think that's changing,
especially if you're not safe and you put in drugs.

CO-CHAIR WEISS: I just wonder. I would like to put the question, I suppose, to the clinicians in the room, and that is: how do you use the results from this kind of a population-wide measure in your practice in dealing with the individual child, if you know, for example, that the child comes from a particular part of the community or the state or whatever -- where maybe the incidence of responding to this question in more urgent terms is higher? What do you do with that information?

CO-CHAIR HOMER: I think there are several things you do. One is, as a health professional, get involved in advocacy around your community. No. 2 -- really going to Goutham's point. You would also explore -- I mean, if somebody would report this to you on a clinical level and they said they were unsafe and you could then explore issues
around bullying, for example, and strategies
for dealing with peer interactions and how you
might approach that. So I think there are a
variety of things you could do.

CO-CHAIR WEISS: And this would be
equally good or better measure than a straight
patient history?

MEMBER LIEBERTHAL: I don't see
this in the clinical office on a patient-by-
patient basis. Again, it depends on where
your practice is and the neighborhood that
your patients come from. It may color your
history taking globally, but I don't know that
it does on a patient-by-patient basis.

CO-CHAIR WEISS: Okay. Just in
the interest of disclosure, my sense is this
is an important question to ask, to get kind
of a complete picture of how children are
growing up in America. My sense also is that
it has greater application in the juvenile
justice arena, or perhaps in housing or areas
outside of medical care.
CO-CHAIR HOMER: Tom.

MEMBER McINERNY: Yes. I think some of the recommendations you would make would be if they don't feel a neighborhood is safe and you say your child needs some exercise and why don't you have your child walk around the block five times, that's not going to be a very good recommendation in a nonsafe neighborhood.

You are going to have to figure out something else, and maybe get a treadmill downstairs or something so that they can exercise within the home or wherever they are as a safe place, those kinds of things. This does get to the millennial morbidity and it does get to the Academy of Pediatrics as having the residents understand sort of the pediatric links with the community type of thing, understanding the environment your patient comes from. It's very important for you to understand a whole bunch of things about them, and how you recommend that they
provide care.

CO-CHAIR HOMER: Sharon.

MEMBER DOCHERTY: That just made me think about high-risk behavior, and understanding what potential high-risk behavior they may be involved in, based on the community they live in.

MEMBER ZIMA: I was thinking in that line as well and also the higher risk of exposure to things like drugs and guns. Then I think clinically, even though this doesn't relate to the indicator, you are always wondering about violence in the home as well and that would probably come up clinically if this indicator came up positive.

MEMBER JENKINS: The other thing on my mind, and I'm struggling with this obviously, that's why I asked all of you, is Nancy's comment about scope and what's changing and thinking about terrorism, thinking about 9/11, thinking about the reaction of the pediatric community, the
children and their reactions to 9/11.

I guess maybe from that perspective if we're going to incorporate it as a child health indicator at the population level, it's relevant. If so, I would suggest that this is a very good way to ascertain it at least every four years. It's a direct question, it's about perception. It's from a broad-based survey across the country.

MS. McELVEEN: I think it might be worth having our vote on importance and then also scope.

CO-CHAIR HOMER: All right. So let's vote on the importance. That is either an up or down vote. How many are in favor of -- view this as sufficiently important to pass our threshold for subsequent consideration?

DR. WINKLER: All but one.

CO-CHAIR HOMER: How many do not feel it is sufficiently important? All right. So let's move on then to the scientific --

MS. McELVEEN: Do you want to do
scope?

CO-CHAIR HOMER: Scope is a separate question?

MS. McELVEEN: It can be sometimes.

CO-CHAIR HOMER: Well, okay.

DR. WINKLER: I think only because members have raised the issue.

CO-CHAIR HOMER: Okay. So, again, I think we've had a pretty robust conversation as to whether it's in scope or not as a broad outcome measure. How many believe it is within scope for our consideration? About the same.

And how many believe it is not within the scope? One. All right. Good. Okay. So now let's move on to the scientific credibility or acceptability, that's the word, of the measure. Seems like a straightforward question.

MEMBER JENKINS: It's well specified. It's a single question off the
survey about perception as we discussed.

CO-CHAIR HOMER: Let's see, my
little thing says it's really one question.
It's section K10, question 40. Right?
Children whose parents report their
neighborhood or community is never safe for
children, sometimes safe.

DR. WINKLER: It's defined as
usually and always safe.

MS. BOSSLEY: It's right under
your numerator details on 2a.3 as projected.
It is split into two. You're right, they've
got two questions: how often do you feel the
child is safe in the community or neighborhood
and would you say never, sometimes. They just
get to the ranking of it.

CO-CHAIR HOMER: Okay. So it's no
and then how bad it is. So do we feel
comfortable making votes about the scientific
acceptability? How many feel it completely
fulfills the criteria for scientific
acceptability?
DR. WINKLER: Ten.

CO-CHAIR HOMER: How many feel it partially meets the criteria? Okay. Is that everybody?

DR. WINKLER: Yes, it is.

CO-CHAIR HOMER: Okay. Good.

Okay. And then moving onto the usability.

Any discussion? So on the general population every four years because of special health care needs would presumably get this question. I don't know. Can we ask our steward?

MR. STUMBO: It's actually not in the other survey.

CO-CHAIR HOMER: Okay. So this is every four years. Harmonization, again, there are lots of other measures of community wellness and exposure to safety and violence. I just did a session on the EDI which is being used across Canada and Australia and Orange County and a bunch of other places like that. I guess none of those have been submitted so we don't have to worry about them.
MEMBER FISHER: I think what I see about this is that this has been used before and I think it would be important to keep using it and it may be that we need it more frequently just to see how things are changing over time. The fact is -- and also to get rid of some of our perceptions because I think that about feeling safe it is changing.

As Kathy brought up, I have to say that when I thought about someone setting that bomb off in New York, I was thinking, oh my God, this is going to be like when I went to England and I didn't go to Harrod's and I didn't go to some stores at Christmas time because I'm worried about the IRA because that's a reality. To me it's a big difference.

The other thing is even in neighborhoods, I had a friend in Detroit that I was talking to on the phone, on my cell phone, as I was going to the ATM at 10:00 at night yelling at me about going to the ATM at
10:00 at night.

I was trying to tell them that I was not in Detroit and where I lived I could have even jogged to the ATM at 10:00, but I couldn't jog. I just had knee surgery. The person was really screaming at me and I'm thinking, no, no, no, I don't live there. As I travel across the country, I perceive myself as safer in some places than in others. I just think this is a really important thing. I think it affects your life and it's going to affect our health. It's not just poor people that have guns, you know. There are a lot of wealthy people with lots of guns.

CO-CHAIR HOMER: All right. Did we already vote on usability then?

MEMBER FISHER: No.

CO-CHAIR HOMER: So let's vote on usability. Does it completely fulfill the criteria for usability? Does it partially fit the criteria for usability?

MS. WAUGH: It's everybody at 14
for partially.

CO-CHAIR HOMER: All right. So let's then take an overall.

DR. WINKLER: You need to vote on feasibility.

CO-CHAIR HOMER: Ah, sorry. How could I forget that? We're doing all right. Feasibility. So this is a survey measure. Just like all the other survey measures this is every four years. Presumably there is some level of inaccuracy, as Allan has mentioned. Okay. How many feel this completely fulfills the feasibility criteria?

DR. WINKLER: One.

CO-CHAIR HOMER: How many feel it partially fulfills it?

DR. WINKLER: Everybody else.

CO-CHAIR HOMER: Okay. All right. Now we can move to the global recommendation.

MEMBER McINERNY: One quick -- what's to stop a pediatrician when they are doing their annual health assessment to ask
the parent, do you feel your child is safe in your neighborhood?

CO-CHAIR HOMER: I believe there is a whole kit that the academy has put out about violence prevention and all that from Bob Sege and company. Does it include this question or not? Do you know?

MEMBER McINERNY: I don't know.

MEMBER LIEBERTHAL: There is nothing to stop a pediatrician from asking the question about the safe neighborhood just by looking at where they live already should know whether it's a safe neighborhood. Whether they are safe in their home is a different question.

MEMBER McINERNY: Or did they feel safe is the question.

MEMBER LIEBERTHAL: Or safe in the school.

CO-CHAIR HOMER: Let me go back and call for a vote for all those in favor of recommending endorsement of this measure. The
short answer is you measure late in the day.


So moving on then to our very last measure: children who live in neighborhoods with certain essential amenities.

MS. McELVEEN: So it sounds like some of the same discussion.

CO-CHAIR HOMER: Similar but not the same.

MS. McELVEEN: Some of the same discussion points may come up. This measure creates a count or a composite measure designed to assess whether or not children live in neighborhoods which contain elements that are known to have an impact on health, status, and functioning.

CO-CHAIR HOMER: And what are those measures?

MEMBER RAO: Sidewalks.

MEMBER JENKINS: This says you need to have all and all includes -- sorry.

Give me a sec. Sidewalks. Go ahead. If you
have them you can read them.

MEMBER McINERNY: Sidewalks, walking paths, a park or playground area, a recreation center or community center and a library or a bookmobile.

MEMBER JENKINS: To me, I guess, I have my same question in terms of importance as before. They all sounded great. All children should have them. On the other hand, was this a child health outcome measure I wasn't sure and was going to ask the measurement developer and panel about scope and about the link to the kind of rationale for this being a child health outcome measure.

CO-CHAIR HOMER: I might comment this one sounds more structure and processy. The other one was a perception of safety which is an experience which can have a pretty clear biologic correlate. Well, this one is basically do various services and programs exist in your community which may be correlated, but in that sense it's more like
either a structural measure, you know, what is
the nursing ratio in your hospital, or a
process. More structure than anything else.

MEMBER FISHER: I don't think a
sidewalk is an essential amenity. I'll just
say, okay, there are some very, very nice
neighborhoods that do not have sidewalks.
There is one here because I think I was on
Wisconsin in Georgetown and I can't even tell
you where people took me. I didn't even know
this neighborhood existed where I could
probably afford a quarter of their driveway.
Is it this Fox something?

Foxhall, yes. They don't have
sidewalks and there are suburbs that don't
have sidewalks.

CO-CHAIR HOMER: But they are
not -- this is on the structural thing so this
is part of the issue of creating health,
promoting healthy eating and active living and
all that sort of stuff.

MEMBER JENKINS: The developer
leads it in the same way as they did with safe neighborhoods to physical fitness.

CO-CHAIR WEISS: Let me also mention as the mother of an architect who does a lot of city planning and so forth, there is a bit of a difference of opinion within that community. There are those who say that greenery is more important than pavement. Whereas it's important to have a safe place for children to play, the tradeoff between whether it should be a paved environment versus grass and such is a real debate.

CO-CHAIR HOMER: You campaign against sidewalks?

MEMBER LIEBERTHAL: Parks and playgrounds may be among the most dangerous places in the city.

DR. WINKLER: I would like to ask the measure developer what the evidence --

CO-CHAIR HOMER: I'm sorry. Let's ask the measure developer.

DR. WINKLER: Could we ask the
measure developer what the evidence is that
this measure is based on for both the
sidewalks and the playgrounds in terms of the
relationship to health outcomes for children?

MS. ELDRED-SKEMP: I'm not exactly
sure, but the measure is new, it was just in
the 2007 report, but I know that the technical
expert was involved in this issue. But I'm
not sure about this particular measure.

MEMBER RAO: These are all
measures of what is called a built environment
which is associated with rates of obesity and
other health-related behaviors. They are
legitimate measures. Most of the data comes
from epidemiological type studies that
correlate these characteristics with better
health and it's a pretty strong correlation.

There are actually some, a very
small number of studies, that show a
transition that when you improve the built
environment, children's health does improve
within the following years so very legitimate
question.

MEMBER JENKINS: The libraries are included and is that true in the composite format as written with all four?

MEMBER RAO: The libraries I don't know about.

CO-CHAIR HOMER: I mean, my sense more we're talking about environments to promote physical activity which are related to obesity. A library I think is just another important element of intellectual development. I think we have actually done -- I think from an importance perspective I guess I would say either importance or scope I think we are having a hard time getting our heads around this.

Why don't I call for a vote on whether this meets the scope? Should I do scope first or importance? Anyone care? My call? I'm going to say scope first because, again, I think these are more structural measures that are not as clearly linked to
outcomes as some of the other ones.

How many believe this falls within our scope of work? Raise your hand. I see none. How many feel this does not fall within our scope? There you go. I think that's basically a threshold measure.

I think we can take this one off and feel good that we actually not only tabled a measure but actually turned one down that won't be coming back to us until we get constituted as a structured committee as well as a process committee.

MS. McELVEEN: Okay. That does conclude our measures that we were assigned to review today which only sets us up for much more fun tomorrow. We have our plate full.

I quickly just wanted to mention to the group and I will also remind everyone tomorrow that we will follow up with everyone regarding your availability and willingness to serve on this phase two to look at the CHIPRA measures.

Also we will be scheduling a conference call
fairly soon.

I want to say within the next two weeks hopefully to look at some of these measures that we have tabled. I just wanted to kind of put that in your ear now. We will try our best to get something out as soon as possible in terms of nailing down your availability for that. I just wanted to mention that to the group tonight.

Preparing for tomorrow, one other thing. We are reviewing a measure in the morning. It's a measure called healthy term newborn. The measure developer did send me a sort of visual schematic of that measure that may help understand it. I may just forward that to the group tonight just so you can look at it and have it for tomorrow.

Are there any questions from anyone about anything?

MEMBER PERSAUD: Are we starting earlier tomorrow?

MS. McELVEEN: We are. Thank you.
Yes. We are starting at 8:30 tomorrow. 8:00 breakfast, 8:30 we'll be ready to start up
again. Any other questions?

CO-CHAIR HOMER: Are there any
members of the public?

MS. McELVEEN: Are there any
comments from the public or audience? You'll
have all the comments tomorrow, right?

CO-CHAIR HOMER: Okay. Good.

MS. McELVEEN: Okay.

CO-CHAIR HOMER: Thank you all.

MS. McELVEEN: Thank you, guys.

Have a good night.

(Whereupon, at 4:39 p.m. the
meeting was adjourned.)
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