THE NATIONAL QUALITY FORUM

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MEETING OF THE CHILD HEALTH STEERING COMMITTEE

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FRIDAY
NOVEMBER 13, 2009

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The Child Health Steering Committee met in the Ambassador Room of the Hilton Washington Embassy Row, 2015 Massachusetts Avenue, N.W., Washington, D.C., at 10:00 a.m., 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
SHARRON L. DOCHERTY, PhD, CPNP (AC/PC)
KATHY J. JENKINS, MD, MPH
ALLAN S. LIEBERTHAL, MD, FAAP

THOMAS McINERNY, MD
MARLENE R. MILLER, MD, MSc
LEE PARTRIDGE
JANE PERKINS, JD, MPH (via telephone)
DONNA PERSAUD, MD
GOUTHAM RAO, MD
ELLEN SCHWALENSTOCKER, PhD, MBA

BONNIE ZIMA, MD, MPH

NQF STAFF PRESENT:
IAN CORBRIDGE
MELISSA MARINELARENA
ASHLEY MORSELL
EMMA NOCHOMOVITZ

REVA WINKLER, STAFF
BONNIE ZELL, STAFF

C O N T E N T S

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

9:08 a.m.

CO-CHAIR HOMER: So now I can say it again with the microphone. Good morning, everyone.

PARTICIPANTS: Good morning.

CO-CHAIR WEISS: And good morning. Delighted to see all of you looking so ready to go.

CO-CHAIR HOMER: So I'm sorry. Reva, you said something about --

DR. WINKLER: We want to have the operator open the lines to see if anyone is on the call.

THE OPERATOR: All lines are open.

DR. WINKLER: All lines are open. Is anyone on the line?

MS. PERKINS: Jane Perkins. I'm here. Hello. Good morning, everybody.

DR. WINKLER: Hi, Jane. Thanks for joining us again.

MS. PERKINS: Thank you for having

me.

CO-CHAIR HOMER: So it sounds like there was some enjoyable evening activities. It sounds like Kramer's Books was a good place for dinner. Perhaps we'll make a note of that for future meetings.

So we have a good day today. Reva also tells me that the staff was extremely productive and has a lot to share with us today. So we're looking forward to that.

So with that it says "Welcome, Introductions, Brief Review of Day 1." Do you want me to review Day 1 or will you be reviewing it? Go ahead.

DR. WINKLER: As always happens, Day 2's agenda always gets shuffled based on what happens on Day 1, and so this morning we've pulled together some of the things you've talked about, brought in some of the information you were asking, and we'll go over that minutes, and that's sort of a review of yesterday.

We've also drafted up some language for the call for measures for you to look at based on your conversation yesterday, and then we're going to need some input from you all on who to target this call to to help us distribute it appropriately.

Then I've also got a draft of a potential framework for you to take a look at and think about and opine upon. And so the last thing we'd like to do is go over NQF standard evaluation criteria. You received it in your materials, but you will be evaluating measures, and so just as an introduction and also when you're thinking about measures that might be out there to submit, realizing that they will be judged against these criteria and kind of knowing what the lay of the land is might be helpful in targeting and looking for measures out there to get submitted into the project.

And then we'll just talk about where we go from here. Quite possibly we'll

be done around lunchtime, and luckily the weather seems to have improved from when you came in so that hopefully traveling out won't be as uncomfortable as it was when you arrived.

But that's what our plan for this morning is, and I'm hoping for everybody to react. We're looking for your input significantly because it will help kind of determine where we got next and how we guide the work that we're going to do.

So there were a couple of things that you were talking about yesterday, information we wanted to get to bring back that you talked about, but we didn't have details on. And so one of them was you were talking about the CHIPRA core measures, and what I did is I pulled the set of 25, the recommended set off the AHRQ website, and I did two things. I highlighted those that are NQF endorsed measures, and I also assigned those that I thought were outcome measures.

And you can see that some of them are certainly NQF endorsed measures. Not that many of them are outcome measures, and we could probably have a discussion on whether on the assignment of outcome or not, but you can see where we are. There aren't that many outcome measures, and most of them that are are already in queue as endorsed measures.

So you can kind of see that the work NQF does plays a significant role in this sort of things. The two outcomes measures, and again, are they outcome measures; are they ER visits sort of in general I assume; and then the asthma patients greater than a year of age with more than one asthma ED visit. That seems to be the only outcome measure in there.

But there are several others, and they are already within NQF's portfolio. So that's just a bit of a follow-up.

Question, comment?

DR. LIEBERTHAL: Whose measure was

the asthma greater than one year with an ED visit?

DR. WINKLER: Don't know right off the top of my head. I didn't capture that. It's on our website. We can go back and find out.

DR. LIEBERTHAL: The NCQA, virtually every criteria for asthma or measure for asthma starts at five years because under five years it's very difficult to know what to call asthma. There are so many other conditions, and it's a very different disease under five years of age than over five years of age. So I have a problem with that as a measure.

DR. WINKLER: Right. Well, just because we were talking about it, I thought I'd actually just bring the list and show where we've intersected. As far as I'm aware, all of the measures, and they're all process measures that NQF has endorsed. They are as you say. The NCQA started five years kind of

measure.

So that was one thing that we did to kind of follow up on what you were talking about. Another one that we were looking around for, you know, the top 20 for children, not easy to find, but we did find this is sort of a summary article that AHRQ put out from, you know, all of the data they crunch. It's amazing. They don't do a top 20 diagnosis for children. You can't find it anywhere, but we did find the top five most costly conditions in children in the annual cause. I believe this is 2006 cost data.

And so, you know, there it is: depression and asthma, trauma, acute -- that's bronchitis, but isn't that misspelled? Yes. Okay. I was going to say I tried to read it and it didn't work for me. And then acute infectious disease.

So those are the big ones on overall cost basis. Face validity, does that sound right to you all?

DR. RAO: Did you look at the -- yes, there's the National Ambulatory Medical Care Survey. Did you have a chance to look at that?

DR. WINKLER: I did, and answering this question, isn't it in that published data? If I ran the data myself, I could probably answer the question, but I wasn't doing that last night. I was just looking at the published kind of reports, and there just wasn't a list of, you know, by age, top diagnoses, or any of those sorts of ways. The raw data is there and we could probably generate it, but not last night.

So those are the big ones. The other thing that is useful that comes from AHRQ that I looked at was the hospital discharges. So you can cut this either by volume or by cost. This happens to be the one by volume, and this is, again, 2006 data. I think that's the most recent, and so this is overall for all children, and so as Charlie

mentioned, the most common is newborn, not exactly a surprise here.

But these are broken down into age bands, and so you've got the lesson, the infants, if you will, and so we do have the major diagnoses from hospitalization, and so the one to four, but we're seeing pneumonia, asthma, bronchitis. You know, the respiratory thing is playing a significant role. Dehydration and viral syndrome plays a significant role. School age, same thing. Appendicitis sneaks its way up there, and arm fracture, one of my favorites. I like that.

And then I guess the pre-adolescent, appendicitis, you know, hits the top followed by affective or mood disorder. So we're starting to see mental health. So it's really an evolution over time.

And then for adolescents that becomes the big one, and then maternal complications and childbirth.

So this is one way of looking at

the hospitalization. So you know, this data is here. In terms of the ambulatory care, we'll see if we can mine that out, but I couldn't exactly get it real quick. I don't carry the SAZ program on my computer, even if I remembered how to use it.

So you know, if anybody runs across that kind of general data around kids trying to figure out, you know, we were talking about slicing and dicing it through both cost and volume prevalence or incidence. It would be great if you could share.

Kathy, do you have a question?

DR. JENKINS: Now, the other lines of course is severity or outcome, and I know that CHCA has generated a list of the top mortality diagnoses that I can probably --

DR. WINKLER: Okay. So that's the other one. So essentially volume, cost and severity are the various ways to slice and dice it. It would be nice if we could pull together the data to be able to have those

lists, particularly to see where they intersect.

DR. ZIMA: For ambulatory care you might want to look at the NAMCS.

DR. WINKLER: Yes, we did.

DR. ZIMA: And you didn't --

DR. WINKLER: Well, the thing is they give you the raw data. So we could probably pull it out, but they're actually published tables, which was really all I had time to look at last night, didn't lay it out quite the way to answer the question.

DR. ZIMA: Yes, and that's tricky, too, because the analysis isn't the child. It's not has base visit, and then when you look at the details, there's some exclusion criteria. It's not perfect.

DR. WINKLER: Right. It's around how many visits. If you've got a sick child who's coming in for multiple visits, it counts multiple times rather than one. So data problems always an issue.

So anyway, we've kind of pulled these things together to kind of follow up on your conversations. Is there anything else along this realm, and especially data kind of things you'd like to see if we could gather up that would be helpful in performing or thinking.

DR. RAO: Does anyone know in terms of the attribution of cost to depression, is that mostly in-patient hospitalization that's the cost?

DR. WINKLER: Yes. Well, that's with this, but the previous one that we had up on the top dollar cost, I think it was combined, but -- and I think, again, the data from AHRQ, and it was a summary report, and so I think that if you delve into the data, we can break it down, but again, it's the kind of thing that these were their summary reports, and that was the easiest to grab, but we can probably get that data, you know, by developing different --

DR. RAO: It's probably a small number of children who are stimulating a lot of columns.

DR. WINKLER: Right.

CO-CHAIR WEISS: Reva, can you send that to us electronically?

DR. WINKLER: Sure, yes. These are new things we've just discovered. We'll be happy to package them up and send them along. We can share the, but we can see if we can dig in some of the data and get it broken down a little bit more. We can probably contact somebody over at AHRQ and see if they can get it to us.

So those were the sort of follow-up on what you discussed.

DR. McINERNY: Does Kaiser keep some data like this?

DR. LIEBERTHAL: Not that I'm aware of. We can get the data on what we see the problem may be that the precise coding may be inaccurate. So we're not -- we've only

been coding for about two years, and most of the doctors are not very good at it. So I don't know how accurate the data would be, but it would be interesting to search our database, which does have this information.

I'll give you an example on the coding, is a search for all patients diagnosed as cystic fibrosis, and looking to see if there are any that are out there that haven't been referred to the CF Center, and we've got a couple of hundred, and over half of them are things like fibrocystic disease of the breast or something like that.

CO-CHAIR HOMER: Oh, my goodness. Given the sponsor, it might be worth checking with CMS as to their expenditures by condition, if we could get that.

DR. WINKLER: Yes. That's always a real interesting query.

DR. McINERNY: Well, you know, for Medicaid, you need to check with 50 different Medicaid programs.

MS. PERKINS: I don't know if they still do it, but some years back Robert Wood Johnson published data on ambulatory sensitive hospital stays, and I think it was for kids.

DR. WINKLER: Right. Commonwealth produced data, too.

MS. PARTRIDGE: Actually with respect to CMS, they have invested a substantial amount of money in merging all of the data that the claims take. Remember it's admin. It's coming off paid claims, and they've merged it, however, so there is something of a national database. I suspect there's nothing more recent than 2006, but I think Mathematica may be sitting on some of that and could do the analysis, and I'll be glad to ask my former colleague, Jim Verdier who used to run Indiana Medicaid if that, indeed, is there and we can share.

DR. WINKLER: Yes, that would be great.

DR. LIEBERTHAL: Does NHANES

collect that sort of data?

DR. WINKLER: I don't know. That's something -- I think they collect some of this kind of stuff, but maybe not in the exactly the way we're asking the question. That's something Bonnie might be able to help us with.

Do you know if NHANES collects the kind of childhood diagnoses?

We can find out.

DR. McINERNY: The only other, I would wonder if somebody like UHC, United Healthcare which has, you know, huge numbers of patients, and that's commercial but you could probably extrapolate if they would release it. I don't know whether they consider it proprietary.

DR. WINKLER: They tend to.

DR. McINERNY: Yes.

DR. WINKLER: Yes, in conversations.

CO-CHAIR WEISS: Let me just say

that we have worked with Thompson Healthcare in the past, and they have an aggregate database of about ten million lives. It's all from the private sector side, and they have been very cooperative in helping us with certain codes and so on. So it's another possibility.

DR. WINKLER: Yes, okay. All good options. So we'll see what we can pursue to come up with that kind of information.

The next thing in terms of follow-up is the rather lengthy discussion we had around -- oops, this isn't what I meant to get -- around the call for measures. Now, somehow I am struggling with myself here. I pulled the wrong file.

But I drafted a -- sort of redrafted that list that you talked about yesterday. Where did it go? Draft call. Here it is. Thank you, finally.

In terms of the bullets we went over and so I want to share what I kind of

drafted up if I can get it on the right computer. Bear with me just a second.

So just for Marina's point, outcomes up at the top of the page. This is sort of boilerplate background, but here is where we're really talking about what we were working with yesterday, and how is it to point to C? Not that easy? Yes, that's what I was just about to do. That's where I was going. Come on. I want to zoom. I'm trying to get 150.

Yes, well, that will do it. Okay. So this is actually the meat of the call that we did, and so a couple of -- you know, I tried to change it in response to what you were talking about yesterday, and this is where, you know, continue to help working on this. The first bullet I just allocated to functioning because we talked a lot about functioning, both child and family, including maintenance or improvement as well as attaining optimal functioning. So all of

those, I think were elements that you were -- that were highly desirable, and so I made them as explicit as possible, and I separated out what had previously been with that bullet, symptom improvement or relief. We didn't talk very much about that, and then added a bullet on growth and development to include physical, cognitive and social, all of those things.

And I think we said the physical fitness kind of thing, developmental milestones, that kind of rolled into that area.

Then that one bullet that you had trouble that seems kind of messy, I broke out patient or parent reported outcomes, such as health status or health related quality of life because we do see those.

CO-CHAIR WEISS: Let me just ask. I think Allan made the point yesterday or someone did that in the patient or parent reported arena we needed to use some sort of objective structured measurement tool so that

it's not just casual.

DR. WINKLER: Right, okay. Report outcome tools for -- what's the word? Standardized, that's the word. Health status or health related qualify of life assessment?

DR. McINERNY: Would that include something like the PAN symptom checklist?

DR. WINKLER: Possibly.

DR. McINERNY: All right, and then the ADHD like the Vanderbilt?

DR. WINKLER: Yes, yes. Well, I think it depends. Remember there are other specifications beyond the took. When do you use it? Who do you give it to? How do you interpret the results? How do you use those results to assess quality?

So there are other elements besides the exact tool that would create the measure, but then so anything else on that? Okay.

Do you want cognitive? Do you want emotion? Works for me.

DR. SCHWALENSTOCKER: Could I ask one question about the one above that?

DR. WINKLER: Sure.

DR. SCHWALENSTOCKER: Physical fitness seems to me to go better with the first one than the growth and development, but maybe I'm --

DR. WINKLER: I don't care.

DR. SCHWALENSTOCKER: Well, I defer to the physicians in the room, but --

DR. WINKLER: You were the one that kind of had the physical fitness thing yesterday. So I put it in because you talked about it.

Where would you put what?

The first bullet there.

DR. RAO: I intended physical fitness to be under the first bullet.

DR. WINKLER: Oh, okay. That was me. Sorry. I can fix that.

CO-CHAIR HOMER: So moving to a different bullet, the compliance with

treatment, I'm not really comfortable with that as an outcome.

DR. WINKLER: Well, this was sort of what you were talking about on that one bullet you didn't like about knowledge, self-management, yaddy-yadda-dah, and the words you tossed out were kind of compliance with treatment, you know, behavioral change doing something.

DR. JENKINS: Is it adherence?

DR. WINKLER: Okay. Adherence, compliance.

DR. LIEBERTHAL: Adherence is more PC now -- but I think that is an outcome because if you can measure adherence based on your intervention, then you measured -- it may be an intermediate outcome, but it is an outcome because the treatments from many of these things have proven successful, and the failure is the appearance.

DR. McINERNY: I think some examples might be seatbelt use, bicycle helmet

use, as an intermediate outcome.

DR. WINKLER: How about medication adherence?

DR. LIEBERTHAL: Why are you less comfortable with it, Charlie?

CO-CHAIR HOMER: I guess it's an intermediate outcome. I just tend not to think of that. I mean, I think of adherence as a step along the process to improved outcomes. So, you know, it's part of the treatment. You're not writing whether you prescribe. It's not a process here.

We would put it in here and see. I think we'll get back a bunch of measures of adherence. I think the question is whether we really consider that to be a quote, outcome measure.

DR. WINKLER: We actually have endorsed a fair number of medication adherence measures fairly recently in a medication management project. So --

CO-CHAIR HOMER: Do you view that

as the outcome?

DR. WINKLER: We didn't really have to say it was an outcome in our process, but that was sort of a --

CO-CHAIR HOMER: So maybe we're splitting hairs.

DR. WINKLER: Yes, I do think that there is a vagueness to it, and it sort of depends on your point of view, but --

DR. JENKINS: I do agree that it's intermediate. So it's an intermediate in one of the others. I'm wondering if there isn't a way to say that intermediate clinical outcomes with definite links to clinical outcomes, to clinical outcomes, will be considered and put them all together, and adherence would be part of that for me.

CO-CHAIR HOMER: I mean, I differentiate, for example, the outcome of counseling about or legislation to change seatbelt use. Whether you are smoking, for example, it's an outcome to me of whether the

person stops smoking or not.

DR. WINKLER: Yes, it's decision weight.

CO-CHAIR HOMER: Right, which is the behavioral change.

DR. WINKLER: Right.

DR. JENKINS: Or adherence. I mean, that is adherence to counsel.

DR. WINKLER: Okay, or adherence to whatever therapy you recommend.

DR. RAO: Reva, what kind of measures are you getting for medication compliance? Are they like co-counts or --

DR. WINKLER: Yes, it's medication possession ratios, is sort of the most common one, and actually they landed on sort of a standard definition for medication or for medication possession ratio.

DR. RAO: These are for adults with heart failure, things like that?

DR. WINKLER: Actually across the board, and some of them actually could apply

to kids. I have to go back and look at the actual specs, but you know, it was statins. It was some of the mental health meds or schizophrenic medications actually, as well as, you know, the beta blocker, you know, the usual stuff.

DR. ZIMA: This is just a wordsmithing, but I think I'm again back on thinking about what Charlie is struggling with. Maybe it's adherence with treatment, comma, behavioral intervention, not necessarily change, just to have two nouns there, and that we think goes to the point about counseling.

DR. WINKLER: I guess one of the things I'm thinking about with, you know, the behavioral intervention, the outcome, is as a result of your counseling did they do anything. Did they change something?

CO-CHAIR HOMER: I think the heading is behavioral change. That's the lead.

DR. WINKLER: Okay.

CO-CHAIR HOMER: And then adherence which he meant is actually part of the example, medication adherence. I think that probably captures it.

DR. McINERNY: You could maybe use another example. You could put in smoking cessation.

DR. WINKLER: Happy? Does that work?

Donna, please.

DR. PERSAUD: I know Kathy said this, and I don't know if we adjusted the document to reflect that, whether either in the introductory or in these bullets we specify that we're primarily searching for outcomes measures, but if they are processed or intermediate, those are acceptable submission as long as you show clear linkage to a specific outcome measure.

DR. WINKLER: Yes, I think actually really we don't want to open the door

to process measures because that's essentially what the rest of the NQF portfolio is, but intermediate outcomes, and I think that's why we are trying to get this list of bullets right, to describe what we mean by outcomes, because, again, the term may mean different things to different people.

So what are we including in this project as being the outcomes of interest or desirable outcomes? What's the breadth, but what are the limits?

So I would be uncomfortable, you know, saying that we're accepting process measures because that's really not what we're trying to do. Intermediate outcomes, which is why it's one of the bullets, is perfectly reasonable.

Right, but at this point what Melissa is bringing up is we've seen lots of measures around smoking cessation counseling, and we're trying to be sure that the measure we have is one measure applicable to everybody

as opposed to multiple little ones, but harmonized, you know, looking to see if the smoking cessation measures we have actually including children.

As it turns out, the endorsed set right now has two measures, one for adult, one for children. They're identical, but there are two. So merging.

So to the degree we have some of these sort of cross-cutting, generic things that really aren't, you know, population specific, we don't want multiple little measures for all of the different populations. We like one measure that would apply to everyone.

CO-CHAIR HOMER: I mean, the relevant pediatric measure which maybe would come in here is actually going to be initiation or lack thereof of smoking. So actually that would be something I'd be interested in getting in this call because that's --

DR. WINKLER: Prevention would be even better.

Lee, you've been patiently --

MS. PARTRIDGE: Sorry. I'm sitting here struggling with patient or family experience with care because in the NPP work we see that as having three dimensions. One is the experience. Are you satisfied with the care that you receive, been your experience with whomever, your health plan, your physician, your hospitals, your home health agency?

But the other two are shared decision making, which is sort of part of the knowledge concept, I think, that we were flirting with yesterday. To the extent that you have a family very much involved in trying to decide how you're going to handle the condition or treatment of your child, and then the third, of course, is developing family and patient capacity for assuming more management of their own care.

And it seems to me we need somewhere in here to reach out to the prospective developers and senders and say, "We would like to have something around measurement of parent and patient involvement in their care," not just a passive "did you adhere to the treatment plan," but "were you involved in developing the treatment plan?"

Development, developing the treatment plan is a process measure. It's not an outcome measure.

DR. WINKLER: Right.

DR. JENKINS: Lee, I was thinking maybe that second half of what I think you're alluding to, which is the whole shift that we talked about yesterday to a chronic disease management model where for a portfolio of patients, clinicians are actively managing patients whether they're in their viewpoint or not that day.

And to your same point, the families are also part of that story, and I'm

not sure if that's all wrapped into the clinical outcomes at the end or somehow moving toward that different type of management model should be more explicit. Is that part of what you're thinking?

DR. WINKLER: Are there intermediate outcomes that you're thinking of, Lee? Because ultimately the end is, you know, did they do well for whatever you're being treated for, but are there intermediate outcomes, such as for the shared decision making. The parent-family perception that they had a lot to say in the decision making process, is that an intermediate outcome in this kind of situation?

DR. LIEBERTHAL: I think it is.

DR. WINKLER: Okay.

CO-CHAIR HOMER: So I think the way to do it if we wanted to would just be to put a parenthesis after the patient or family experience with care and list those three dimensions that you mentioned, which could be,

you know, ratings, comma, shared decision making, comma, and --

DR. WINKLER: So one is satisfaction, right?

DR. JENKINS: The other one is value, value from the perspective of patients and families, which is another new paradigm.

DR. SCHWALENSTOCKER: And then there's the efficacy, talk about patient efficacy or family efficacy in making the illness, kind of getting it to your chronic care.

CO-CHAIR HOMER: I think the capacity for self-management, does that capture that concept?

I guess the only question I'd have and I guess we'll find out when we call, I mean, CAHPS is already an endorsed measure --

DR. WINKLER: It is.

CO-CHAIR HOMER: -- including the pediatric CAHPS survey. So I'd be surprised if we'd get anything better. I mean, there

might be narrower measures.

DR. WINKLER: I was going to say aren't there some disease specific survey type tools --

CO-CHAIR HOMER: DR. RAO: Yes, there are.

DR. WINKLER: -- looking at some of these elements? So you know, whether we want to break them down and have a library of these little things --

CO-CHAIR HOMER: There are.

DR. WINKLER: Yes. That would potentially capture some of those.

DR. ZIMA: This is a minor point, but I'm responding again to I think the AHRQ, and if no health is going to be here, maybe a few more triggers in there about mental health. So symptom improvement, really for example, pain control, asthma control, you pepper in there something, either decreased hyperactivity or decreased oppressive symptoms, something that has a mental health

to kind of trigger that we're going to be open to mental health outcomes as well. So symptom would be improved hyperactivity, reduction in depressive symptoms, something like that.

DR. McINERNY: I'm blocking on the names, but the two folks from Crotched Mountain have the medical home survey.

Carl Cooley, right and McAllister. You're right.

I don't know as we need to put it in there, but for smoking cessation there have been some efforts to try and get parents of kids who have things like cystic fibrosis or asthma to stop -- get the parents to stop smoking. So far I think most of those efforts have not been terribly successful, but I think it is an important outcome for the kids if you can get the parents to stop smoking, and I don't know if we need to actually specify that, but it would be interesting to see if anybody comes up with that as a measure, outcome measure.

DR. RAO: The whole issue of environmental health is the home environment, especially with respect to obesity. The built environment plays a role, but how you define outcomes and measures for that sort of thing.

DR. WINKLER: Yes, I mean, aren't those really the process?

DR. RAO: Yes, they are process.

DR. WINKLER: The structure or processes that contribute in the outcome is normal weight or, you know, good breathing.

DR. ZIMA: Could we also add under behavioral change another example, reduced high risk behaviors? I think that would capture this concept of delayed use, substance abuse, driving, all of that.

DR. WINKLER: Reduced high risk behavior, yes. Okay.

DR. JENKINS: Charlie, do you think your transition to adulthood is in the first one? Is it there well enough?

DR. WINKLER: Isn't growth and

development transition to adulthood?

DR. JENKINS: My boss says that everyone should become a taxpayer. That's his goal.

(Laughter.)

DR. WINKLER: Well, very pragmatic. Productive, tax paying.

DR. ZIMA: Just a boilerplate. Again, you're going to be putting in some type of comment that when you refer to it as parent, that you're referring to any sort of primary caregiver.

DR. WINKLER: Right. Yes, I mean, should it be caregiver versus parent? It just seems for children, I mean, it's --

DR. ZIMA: You know, I find if it's in the introductory paragraph that hereafter, you know, primary caregiver is referred to as "parent," it saves text, but then you know, you have Grandma, you have the foster parents, you've got --

DR. WINKLER: Yes, you've got all

the others.

DR. ZIMA: -- the social workers in there.

DR. WINKLER: I'm not sure exactly where it goes right at the moment, but we can add it, yes, right, exactly.

DR. McINERNY: Where do we put something like disease reduction? So that, you know, if you counsel lessons on safe sex, that we have less sexually transmitted illness.

DR. WINKLER: Isn't that an interesting one? Because where's the data that collects them and it doesn't happen? I mean, it's almost a negative.

We tend to monitor the incidence of, you know, various conditions.

CO-CHAIR HOMER: I think that would be included in some of the community health indicators.

DR. WINKLER: Right, but it's still an outcome, is the lack of, the absence

of bad things.

MS. PARTRIDGE: Wouldn't that also be true, say, of community data like suicide? I mean, that it seems to me is a partner with do you screen and counsel for depression.

DR. WINKLER: Well, one of the things I was thinking about was this whole issue around immunization. You know, the rates are such a proxy for disease prevention, but that paired with sort of the big picture, you know, community incidence of immunization preventable diseases gives you that picture. It's one of the things --

CO-CHAIR WEISS: Well, it certainly could be in a category of population-wide measures, community as it compared one to the other or say it's a compared one to the other.

DR. JENKINS: Maybe we could have a whole bullet on like population health, one little circle.

DR. WINKLER: Hold on, hold on.

Because I struggled with trying to figure out how to, again -- I created it as sort of a second one rather than bury it as its own bullet. I went down, "additionally care and soliciting measures to assess populations including," and I had to put something down so you can change it, but I was thinking about the conversation you had around, you know, entire providersþ populations rather than those who just walk through the door.

We were talking about populations that are sensitive to disparities, you know, however you want to slice and dice it, and then the third bullet was the one I have no clue exactly. I just threw something there, was the community concept that I think is what you're starting to talk about, and again I just did not know quite how to --

DR. ZIMA: I sometimes use communities in which health care, dah, dah, dah.

DR. WINKLER: Right.

DR. ZIMA: Sometimes we use the words "child-serving care sectors."

DR. WINKLER: Okay.

DR. ZIMA: And then that encompasses education, child welfare, juvenile justice --

DR. WINKLER: Child --

DR. ZIMA: Child, hyphen, serving care sectors."

DR. WINKLER: -- care sectors, rather than communities.

CO-CHAIR HOMER: Rather than "others."

DR. McINERNY: You know, there are these now improvement partnerships where there are groups of pediatricians, often academy chapters, that work with the state Medicaid folks, and there was a great website, Webinar on that recently led by the folks from Vermont and how several states have significantly improved immunization rates and other conditions by working together, the

pediatricians in the chapter working with the Medicaid folks at least for the Medicaid populations.

CO-CHAIR HOMER: Agreed on both points, but I think what we're trying to get here are measures of population health basically, measures of community health indicators in which health care may have joint accountability with other child-serving whatever the word you used.

DR. WINKLER: Okay.

CO-CHAIR HOMER: Other child-serving programs, but we're trying to find -- again, this would be, for example, the prevalence of sexually transmitted diseases in a population or the prevalence of smoking or the prevalence of suicide, which are conditions that we think are -- so those are population health indicators.

DR. JENKINS: I would use that term. I think we're trying to trigger a more epidemiological mind frame of infant mortality

or whatever, and I don't know if it should be in the header here or just in one of the bars, but to me that's the trigger language of population health indicator.

DR. PERSAUD: Soliciting measures, such as "population health indicators, including" or "measures which are population indexed."

DR. WINKLER: I guess the one thing I would then ask, then does the first bullet make sense for what we were talking about?

CO-CHAIR HOMER: Well, give an example from the first -- what's missing in your first bullet is you're still talking about largely a clinical population, provide a professional practice population. So, for example, if you're looking at your patients with asthma in a clinical population like at Kaiser, that's where you're interested in -- that would still look at, for example, rates of hospitalization or --

CO-CHAIR HOMER: Right, but the denominator would be your entire population, not just who you had an encounter with, sort of the more health plannish maze where you look at the total members with X as opposed to the counters with X that you get off of traditional claims.

CO-CHAIR HOMER: But isn't that what we're going to get up above?

DR. PERSAUD: I think we're getting into higher bullets. We probably don't need that first bullet in the second section.

DR. WINKLER: Okay.

DR. RAO: Reva, I think it would be nice to be much more explicit about this very sensitive population, "disparity" defined by race or ethnicity or geographic location or heart disease status, whatever else we think is important.

DR. WINKLER: What does do you want to put?

DR. RAO: Geographic, rural versus urban, for example.

DR. WINKLER: See what a lousy typist I am. Well, do you want to just remove this altogether?

DR. PERSAUD: I think we can. We're going to get that in the top.

DR. WINKLER: Do you think you will? That's the thing I wasn't sure without being explicit.

DR. JENKINS: My suggestion had been to in the top section put population health indicators

DR. WINKLER: You're right. Of the second one, right?

DR. JENKINS: Well, that was before I knew you had the second session, but will that work?

CO-CHAIR HOMER: You're just suggesting having a bullet in there that says population health indicators.

DR. WINKLER: Oh, I see what

you're saying, rather than a second section. Okay.

DR. PERSAUD: That would be fine.

DR. WINKLER: Yes, we could do this. So what you're saying is population health indicators, such as. Yes? Okay.

DR. JENKINS: Such as infant mortality rates, percentage of suicides, the types of things people are -- what?

CO-CHAIR WEISS: STDs.

DR. WINKLER: Yes, STDs, infant mortality, et cetera.

PARTICIPANT: Suicide.

DR. WINKLER: Suicide, yes. Okay. Let me do this. We'll put it up front.

DR. McINERNY: And the currently correct nomenclature is STIs.

DR. WINKLER: Yes, right, whatever.

PARTICIPANT: Sexually transmitted infections.

DR. WINKLER: So you don't want to

be explicit about, you know, provider population denominators or disparities?

DR. JENKINS: I would definitely be explicit about what Bonnie was referring to, the concept of specific ones with co-accountability are okay when the health care is only one of the accountable individuals.

DR. WINKLER: Is that under the population health indicator?

CO-CHAIR HOMER: Yes.

DR. JENKINS: Yes.

DR. WINKLER: So we want to get rid of this one and this one. No.

DR. PERSAUD: Well, we need disparities and the joint accountability concept in there. Those are the two things.

DR. WINKLER: Okay. This one goes away. So is this one essentially -- I mean, obviously wordsmithing to get the format right, but essentially are we talking about these kinds of things as well?

DR. JENKINS: What may work is to

have a second bullet that says something about populations of specific diseases as opposed to the population overall.

DR. WINKLER: Okay, all right. Got it. So you're saying populations of specific disease states, whatever.

DR. JENKINS: And disparity sensitive measures.

CO-CHAIR HOMER: I'm not sure what that first bullet is getting at. I'm sorry. And, again, it's very hard to write by committee.

DR. WINKLER: Yes, that's fine.

CO-CHAIR HOMER: But I'm thinking you've got the bullet that says population health indicators, such as blank. We have the subheading that say something along the way of your bottom bullet, which is, you know, this includes or this should include, you know, those conditions which are -- in which health care has joint accountability with other child serving sectors.

DR. WINKLER: Charlie wants to put this instead of others, right? Bonnie, you want to leave communities and put?

DR. ZIMA: I'm a little quiet because I'm struggling a little bit with how that last idea about contact and other care sectors relates to some of our earlier service utilization discussion, and that was on your page ahead of that because we hadn't --

DR. WINKLER: We had not finished the entire list of these. So did you want to maybe --

DR. RAO: Let me get back to the disease states. I'm not sure what Kathy intended, but I was thinking more like disabled children and deaf children and mentally challenged children. So I think specific --

DR. JENKINS: Or children with special health care needs. It's just that the denominator didn't necessarily need to be all children, let's say, in the State of

Massachusetts. It could be where some of your prior bullets were going to. That's all I was looking for, Charlie, was to say your denominator doesn't necessarily need to be all children.

DR. WINKLER: But it could also be not only the groups you were mentioning but all of the children with asthma or all of children with diabetes or all children with whatever. Okay. Are we capturing where you want to go?

DR. McINERNY: Could we roll back then to the top? I'm still a little concerned that where we try and assess how physicians are caring for all patient sin their practice, is that somewhere?

DR. WINKLER: That was what I was trying to get with that first bullet. It is a clinical population, but the one assigned or belonging to a provider.

DR. JENKINS: That's also what I was trying to get at with the chronic disease

management. It's really about the denominator, what you include in the denominator for your accountability.

DR. McINERNY: If we get to the specific directions and the specifications, is that where we can put that?

DR. WINKLER: Because this is it. This is it.

DR. McINERNY: That's it.

DR. JENKINS: They do have the sentences above though, the direction ones about the locus, the unit of analysis, and it's conceivable we could just add a clarifying sentence there at the very beginning.

CO-CHAIR HOMER: Yes, because I guess the reason I'm maybe having a little trouble here is that any measure needs to define a numerator and a denominator.

DR. WINKLER: Right.

CO-CHAIR HOMER: So if somebody says, for example, your asthma hospitalization

rate, they're going to have to say how are you defining -- if they're giving us the specification, it's going to have to be some indicator of what the numerator and what the denominator is, and the denominator presumably is going to have to reflect some universe, and that universe has to be either the universe of patients that are -- I mean it could be a visit based universe, one of the patients that I happen to have seen.

DR. WINKLER: Well, our experience in seeing measures like this is measures that tend to be at health plan levels tend to be membership based, whereas measures that tend to be at clinician levels, tend to be visit based.

CO-CHAIR HOMER: I would then include in the top part, say we are particularly interested, you know, for all of these measures, we're particularly interested in measures based on an entire population, including populations within a clinical

practice as well as within a plan or within a geographic community, something like that.

DR. WINKLER: Have to figure out how to wordsmith that in.

CO-CHAIR HOMER: Because I mean, I think, again, when we jump ahead to the reviewing part on the important area, if it was just a visit based, you know, of the patients that I happen to see with asthma this year, you know, I manage to put them on inhaled steroids. I would sort of deem that as less important, but maybe that's too technical.

DR. WINKLER: Well, it's just my experience so far with measures, particularly in the ambulatory care sector are much more that than the population based.

CO-CHAIR HOMER: But I think that's more processes than --

DR. WINKLER: No, it's not.

CO-CHAIR HOMER: So I think if we specify it up front.

DR. WINKLER: Okay. I can't even begin to think about how to do it, but I've made myself the two notes to change the up front to include the explanation on caregiver and that we are particularly interested around the entire population of a plan or practice or whatever.

DR. McINERNY: Now, for example, Peter Slides in Rochester improved the immunization rate of the children in the inner city of Rochester by going and going recall and outreach so that they look at all of the patients in the practices that they were studying and they sent outreach workers out to those that hadn't come in. And that's how you got it from 70 percent to 90 percent.

MS. PARTRIDGE: And that same is true of the medical home discussions where you assume that a physician or practice has the capacity to know how many children are diagnosed with X.

DR. WINKLER: Isn't that one of

the major characteristics of the medical home because you know who's at your house?

(Laughter.)

DR. WINKLER: Who lives at your house?

DR. JENKINS: It's true in a subspecialty realm, too, about management of congestive heart failure and diabetes. It's all of the patients in your portfolio of accountability, not just the ones you have in the -- the concept is fine.

DR. WINKLER: Yes. We'll figure how to work it. We need to think about that one a little bit and redo the front.

There were a couple of these bullets, especially this last one. Allan was particularly uncomfortable with the term "service utilization," but I couldn't come up with anything better. So I just modified it by saying health care services because it seems that maybe health care utilization as a concept, I think, is fairly well understood.

But otherwise I'm open to suggestions. Allan, you were the one that was --

DR. LIEBERTHAL: I'm putting health care services in. I think it clarifies it as what you mean by service.

DR. WINKLER: Right, okay, and then the examples of the readmission.

CO-CHAIR HOMER: The changing condition. I'm sorry. Health -- I don't understand that changing condition phrase.

DR. WINKLER: Well, I think the idea of deterioration or complications.

CO-CHAIR HOMER: I'm sorry. So change in condition refers to defining patient outcomes in that phrase?

DR. WINKLER: Yes, un-huh. Although perhaps we don't need just health care services utilization and then just example; get rid of the rest of it.

CO-CHAIR HOMER: Yes.

DR. WINKLER: Is that sufficient?

CO-CHAIR HOMER: That's what I would think.

DR. JENKINS: Or just say when it represents a change in patient condition. The alternative thing to do here is to make it be unplanned readmissions, unplanned ED or something like that.

CO-CHAIR HOMER: Yes. I agree with Kathy's point. I think you could still say as a practice for a change in condition. I just don't think you needed to elaborate on what -- or a change in --

DR. JENKINS: A change in status.

CO-CHAIR HOMER: -- a change in status, yes.

DR. ZIMA: Just a question because I'm trying to meld that one with the concept of, you know, where do we put outcomes like reducing out of hold placement, reducing, you know, recidivism, things like that.

DR. JENKINS: Maybe I always thought in the population health just to

trigger it.

DR. WINKLER: Bonnie, your microphone.

Where do you want to put it?

DR. ZIMA: Again, maybe it's -- I'm just thinking out loud with the rest of the group. Change that third bullet to content to other child-serving care sectors. That may share accountability, such as school, child welfare, juvenile justice.

I think what we're trying to do is focus on health care utilization for the majority of the outcomes, but at the same time, communicate some type of openness to these population based estimates. So it would be contact with other child serving care sectors, and then take out slash, communities in which responsibility may be shared.

And then, for example, schools, comma, child welfare, comma, juvenile justice, and then I think this is really splitting hairs, but the issue of substance abuse

facilities. Sometimes, you know, it's lumped with mental health. Sometimes NIDA treats it differently. I think I'd like some of the policy experts to maybe help me with that one.

I think that says it.

DR. McINERNY: Under the population health indicators, would you want to put in chid abuse or is that getting too specific?

You can measure child abuse rates. I mean, those numbers are available.

CO-CHAIR HOMER: Such as reports of child abuse.

DR. WINKLER: You want to go up? Is that what you're saying?

DR. JENKINS: Just as a general concept related to what you're struggling with, Bonnie, I want to be sure that we are including prevention, the absence of, all of the absence of including recidivism and things like that, but are we sure we have them?

CO-CHAIR HOMER: That was partly

what we meant by these population health indicators. So maybe that doesn't capture it. So, for example, the rates of STDs or the rates of child abuse.

DR. JENKINS: Well, you were saying before non-conversion to smokers.

DR. ZIMA: Yes. I think this discussion is saying should we have a separate bullet just on safety, you know, which would encompass things like child abuse. It's like patient protection. I don't know if that would be a population based.

DR. RAO: Safety opens up a whole new world of bicycle helmet use, seat belts.

DR. ZIMA: Yes.

DR. McINERNY: There is, you know, David Olds home visiting nurses. His outcomes seem to be pretty solid. That program does reduce child abuse and actually 20 years later his kids seem to be graduating from high school more frequently, those who didn't have the service, but --

CO-CHAIR HOMER: Well, should we just use that as the specific example under the population health indicators, for example?

DR. WINKLER: Which one, high school graduation rate?

CO-CHAIR HOMER: No, rates of abuse reported, rates of child abuse.

DR. WINKLER: Up here?

CO-CHAIR HOMER: Yes.

DR. WINKLER: We might. Someone mentioned it. Bonnie, I think.

DR. ZIMA: I thought substance abuse fit in very well with high risk behaviors. I didn't comment.

DR. WINKLER: Yes, that's typically where it goes.

So essentially what all of these bullets do is define the types of outcome measures that are highly desirable to use for some type of accountability for health care for children. Do they all fit? Are we missing anything?

CO-CHAIR HOMER: I think they fit. I think we need to do some wordsmithing on some of the bullets, but we can do that offline if you want.

DR. WINKLER: Sure. Have we thought about everything, all of the big ones? Anybody got anything that doesn't -- okay. What we'll do is I'll just send this all to you all and feel free. Use that red line.

DR. CLARKE: It seems to me that we've missed the bottom couple of bullets.

DR. WINKLER: Not talked about them? We talked about the health care services utilization. Clinical morbidity from a disease progression?

DR. CLARKE: Well, I think that's pretty --

CO-CHAIR HOMER: Yes your microphone, please.

DR. CLARKE: One of the issues that we run into, you know, how you said, my experience is in acute hospital care, and one

of the issues that we run into is that as mortality rates drop, if you only look at mortality, you're ignoring 96 percent of the patients you treat in terms of their outcomes, and there's a lot of things that happen in acute hospitalized patients besides mortality, and so I think we need to put the appropriate emphasis on the measurement of morbidity.

As I said yesterday, it's not that easy, and you really end up it's very subjective and you really end up using some sort of surrogate, and you know, I would be very interested in seeing what people can come up with to actually put some objectivity into the assessment of, you know, both in hospital and post hospital morbidity.

CO-CHAIR HOMER: Well, it says clinical morbidity. Should we take out the "from disease progression" or should we --

DR. JENKINS: Well, you also have health care acquired hours in event of complication right after it. So between the

two you have morbidity from the disease and then you have morbidity from the health care. So I'm not sure what's missing.

CO-CHAIR HOMER: David?

DR. CLARKE: Well, I just think you ought to probably add morbidity to the second bullet there because that is more --

DR. WINKLER: Which one, survival or where?

DR. CLARKE: No, to the adverse event.

DR. WINKLER: But what about this one?

CO-CHAIR HOMER: The one above says morbidity.

DR. CLARKE: Well, there's that morbidity, but to me that's more of an ambulatory care thing. What you're talking about when you talk about morbidity in hospitals usually is related to your health care interventions.

CO-CHAIR HOMER: Again, is that

different from an adverse event?

DR. WINKLER: Yes, I think what he is talking about, there's the -- are you talking about the difference between -- for every procedure there are a certain level of, you know, not so perfect outcomes, morbidity associated with that regardless of who does it or how it happened and different from the more error based patient safety kinds of things.

DR. CLARKE: Well, I like to say there's no such thing as zero morbidity when you talk about any kind of an intervention.

DR. WINKLER: Right.

DR. CLARKE: No such thing. It might only be inconvenience, but it's not zero ever, and sometimes, you know, if you want to talk about mortality, that represents 100 percent morbidity in my view.

DR. WINKLER: right.

CO-CHAIR HOMER: I'm not disagreeing. I'm just trying to come up with what words we should be adding beyond clinical

morbidity from disease progression and health care acquired adverse events or complications. So just help me. If there's --

DR. DOCHERTY: Could you add to or broaden the clinical morbidity bullet to morbidity from disease progression or treatment or intervention or treatment, or disease treatment?

DR. McINERNY: You maybe want to put it in, for example, line related infections or something like that.

DR. WINKLER: Those are adverse events. Those come under health care acquired adverse events. I can guarantee you.

DR. JENKINS: I think what they are maybe alluding to is something like no logical outcomes after congenital heart surgery. You know, where does that fit in where it's not explicitly that there was a complication or an adverse event?

DR. WINKLER: Is a known risk.

DR. JENKINS: But on the other

hand, that's a very important indicator. It similarly would be, you know, the technical outcome from a congenital heart operation, and the ongoing clinical status of the patient as a result from variation there.

I thought it was captured personally by clinical morbidity and then also spelling out the health care acquired issues so that if I were thinking of a measure and I said does my measure fit in, I would have said yes and put it under one of those two, but maybe you're looking for something more specific than that.

DR. DOCHERTY: I see it sitting there like I think in the population I work with, the bone marrow transplant, the grafters are supposed to be their measures. We measure graphers and hosts. It's just part of that morbidity that occurs because they're getting their treatment.

CO-CHAIR HOMER: So I think that's good. I think we're adding an intervention

and giving an example. Both are examples of grafts versus hosts and neurologic impairment.

DR. RAO: Why are those not adverse events? What's the defining character?

DR. CLARKE: They are adverse events, but you know, I guess my point is one of emphasis. You know, the RFP sort of venue, we seem to really sort of dissected and concentrated on the out patient and so forth, and I agree that that population winds up with most of it, but when you talk about the areas most likely to produce controversy, those are your high risk subspecialties, and we've already seen that in cardiac surgery around the world.

You know, it also happens in other areas of acute hospital care. You know, trauma is a good example. Neurosurgery is a good example, and so forth, and I just think we ought to be a little bit more expansive in describing the requests in this area in

addition to the ambulatory area.

CO-CHAIR HOMER: So do you think, for example, rates of BPD, bronchopulmonary dysplasia, would be something we'd expect to get in this?

DR. JENKINS: In answer to the question about the difference between clinical status outcome and adverse events, using cardiac surgery as an example, would be you could measure the rates of stroke after congenital heart surgery as an adverse event or you could take a population of children and measure their neurological outcomes by neurological assessment tool at five years of age, and they're both actually relevant to our field, understanding the variation in the neurological outcomes may partially be explainable by something that's truly been counted as an adverse event in other cases not explainable by that.

DR. McINERNY: And one of the problems is that things that were accepted at

one point as sort of untoward outcomes that couldn't be avoided, such as line-related infections and ventilator acquired pneumonia, it turns out, well, they really could be prevented if you did the right thing.

And so, you know, that's a significant morbidity that we could prevent if we do things correctly, and we should measure those.

MS. PARTRIDGE: Reva, I'm a member -- well, when we were first talking five years ago with possible measures in the child area, that the pediatric cancer community had quite a bit to contribute, and I wonder if the clinical morbidity, if we might have a cancer example in there. That's not my world, but I suspect there are not adverse events, but normally occurring.

DR. JENKINS: Like rates of relapse.

CO-CHAIR WEISS: Perhaps some of the adverse side effects of the drug

interventions, neuropathy, for example.

DR. DOCHERTY: Or neutropenia is common.

DR. RAO: Just to play devil's advocate, I mean, how are those preventable or how can we improve the quality with respect to febrile neutropenia, for example? That's just going to happen randomly in response to --

DR. JENKINS: I think that's the point, is that some of it is going to need risk adjustment. Some of it is going to be practicing the state of the art where we are, and some of it is going to be something that was viewed as unpreventable. We're trying to focus attention on it. Suddenly neurological outcomes, surgery and --

CO-CHAIR HOMER: I mean, there may be, for example -- well, there are -- the use of variety of drugs to stimulate neutrophil in this case, and different places may be better or less good at using those prophylactically. So that's -- or your choice of therapeutic

agents, things like that. So it would be reasonable to look at that kind of variability.

DR. JENKINS: And advocacy for better devices, better treatments, better drugs, better drugs for children, et cetera.

DR. ZIMA: This is just a question that's I think echoing some of the concerns about prevention. Where do we put things like reducing risk of fetal alcohol syndrome, substance abuse in pregnant women, HIV testing early.

MS. PARTRIDGE: HIV testing is in the perinatal.

DR. WINKLER: Right, but aren't those process measures though?

I mean that's what we're really trying to focus in on the outcomes here.

CO-CHAIR HOMER: I mean, I would hope that, for example, let's say fetal alcohol, somebody may propose that as one of our population health measures, that is, the

rate of fetal alcohol syndrome, assuming you could actually diagnose it reliably in a population or we might end up dealing with that, but that it would seem to me would be a reasonable population health indicator that someone could propose, and we could review and decide whether that -- so I think it should be captured under what we've already defined.

And I agree that I think HIV testing is a process.

DR. McINERNY: And for HIV we can look at congenital HIV infection rates which have fallen off dramatically obviously, thankfully.

DR. ZIMA: Acknowledging the HIV, then maybe that would be one in the parentheses under population health indicator, just, again, to kind of raise awareness that we're -- raise congenital HIV.

DR. WINKLER: Okay.

CO-CHAIR HOMER: The use of the term "rates." All of these are going to be

rates.

DR. WINKLER: Right.

CO-CHAIR HOMER: So we might drop that.

DR. WINKLER: Right, or put it up front, "rates of," da-da-da-da.

Okay. Like I say, I think you've had a chance to kind of work this through, but think about it some more and think of what your colleagues have had to say. Again, the plan is save and send, and yes. So what we'll do is we'll get it out to you.

We're scheduled for a break at 10:30. Do you want to do so? Does everyone need to refill their coffee?

CO-CHAIR HOMER: Does anybody need to check out or anything like that.

DR. WINKLER: That's a good point. There are people looking to check out? Okay. Now would be a good time to.

CO-CHAIR HOMER: So we'll reconvene in 15 minutes.

DR. WINKLER: Yes, and if you're not back, we know where you are. So we'll --

CO-CHAIR HOMER: We'll wait.

DR. WINKLER: -- we'll wait for you.

(Whereupon, the above-entitled matter went off the record at 10:26 a.m. and resumed at 10:54 a.m.)

CO-CHAIR HOMER: So I thought this morning's conversation was extremely productive, and I'm very happy with where we came out. Again, we've had a few miscellaneous comments, but does anyone have any major additions or changes, reflections during the break?

Again, we'll get the chance to see this because Reva is going to save and send it out to us with the time line for when we can review it and give it back to her.

DR. WINKLER: Yes. I mean, essentially where this document is going to go

after this so we'll need to get it to you and get feedback is the call for measures sort of has a two-step process. As Ellen, I think, brought up, sort of announcing to the world at large that the call for measures will be coming, we issue a call for the intent to submit measures or something that has got a goofy title, in my personal opinion, but nonetheless, that's going to go out in December.

We send it to all of our usual folks. We'll send it to you, and you are encouraged, not just welcomed, encouraged to send it on to anyone within your world that you think would find it useful.

So that's the intent. It's sort of an announcement in advance to kind of say this is going to happen.

The actual call for measures is a 30-day call, and that will get up right after the first of the year. We want to avoid, you know, people feeling pushed because the 30

days includes all of the holidays. So it's going to go right after.

And it is 30 days, and we will make the announcement. We will send it out to you. Also the submission is fairly formal and structured in an electronic format, and we're going to kind of show you what happens, but by doing that, it puts it into a spreadsheet that then we can manipulate that data.

When it was in old Word documents or by hand, you know, that was just an awful lot of staff work to manage all of that data, and Kathy has had experience with filling out one of our forms, and it's not an insignificant amount of information. I mean, it's rather pages of detailed stuff, and to the degree that the submitter answers it or doesn't answer it is one of the things you'll be doing in your evaluation.

We're going to talk about the evaluation criteria a little bit because I know David had some questions about are they

required to do this, that and the other thing, and so I'll show you what we're going to be evaluating them on.

But we do need to have people use that form submission process. Work-arounds don't work for us on that particular one. You know, it's a relatively new technical thing for us, and we've been ironing out technical bugs. So anybody who is making a good attempt will work with them.

But you know, we need to have them use the process. So we'll be able to send you out a link to go to this website, submit here, and send them out.

So that's the plan. So the question I would ask you up front --

CO-CHAIR HOMER: Tom has a question.

DR. McINERNY: When you send out the call for measures, will you let us know to which organizations you are sending it so that if we think about an organization and you've

already sent it to them, we don't have to --

DR. WINKLER: Yes, but by the same token I would suggest that if you -- particularly with these organizations you have personal contact, it's one thing to anonymously come from NQF. It's another to come with your name and recommendation on it, you know. In the electronic world duplicates aren't the worst thing that ever happened, but if it's coming with sort of your name behind it, that may carry a little bit more attention. Your E-mail address under sender may prompt someone to open it up rather than ours.

So in that respect that may be of a benefit. I'm not sure duplicates are a problem, but at the same time, one of the things we would like to do is get some input from all of you on who we need to specifically start sending these out, both the intent and then ultimately the call, and I know Charlie was offering up some suggestions to start

with, but just get some ideas and maybe see how together as a group what's your thinking in terms of where you think who would be interested or particularly respond.

Who has got measures out there? Who is doing work in this space, focused on children? Who, you know, is likely to be interested in participating?

You know, because children is not something -- NQF lists tend to have a small amount of children, but your world is all kids. So you're hooked in with them far more than we are.

DR. McINERNY: Well, it's disease specific, such as the Cystic Fibrosis Foundation, the Pediatric Oncology Group, Vermont Oxford Network.

DR. WINKLER: We know them well.

DR. McINERNY: They come to mind immediately. Unfortunately, there aren't as many of these as we should have for children's conditions. There are just some forming. A

new one is inflammatory bowel disease group has a collaborative. I don't know if they have measures, outcome measures.

CO-CHAIR HOMER: They do.

DR. McINERNY: They do?

CO-CHAIR HOMER: Well, they have measures. I don't know if they're outcome measures, but they definitely -- I think they do.

DR. McINERNY: Yes.

CO-CHAIR HOMER: So I had suggested again through the American Board of Pediatrics for several years has convened a group of the pediatric subspecialty group. So I think through ABP we could get access to all of the pediatric subspecialty, medical subspecialty groups anyway. I think that's more medical than -- I don't think the surgical groups are as part of that same group. Maybe they are, but I think that would be one way to get pretty much all of the pediatric medical subspecialties, and that

would be through Paul Miles and Mimi Schaeffer at the ABP.

I also had suggested as you said many of the disease specific groups with the CF being the leading group in this field, but again, I think there are a lot of those. I was trying to think how to get access to them. One I thought was the CDC's National Center for Birth Defects and Developmental Disabilities probably has a pretty good list. CDC has the National Partnership Group that also probably has that, and there's the National Association of Rare Diseases or something like that here in Washington that would probably also have a list of many of those groups like autism.

I think so each of those sort of consumer or parent oriented groups should be informed, some of who will either have measures or will be working with clinician groups that, you know, their medical advisory panels will often be a relevant group.

DR. LIEBERTHAL: I have two questions. One is PCPI requires that their measures have an evidence based guideline to support them. Does NQF have that?

DR. WINKLER: No. We'll look at the criteria. That is certainly one good supporting element for a measure, but it does not have to necessarily be imbedded in a guideline.

A lot of discussion areas or topic areas don't have a lot of guidelines or another interesting problem. We've got conflicting guidelines among various groups. So that's always fund.

But, no, evidence based, yes. You know, studies in the literature, good body of knowledge, but it doesn't have to have been made its way to a guideline per se, though that's a very common route to take. That isn't a requirement.

DR. LIEBERTHAL: Also, I would anticipate that one of the areas where you

will get multiple submissions is asthma, and is it NQF's policy to approve multiple measures in a field, or what do you do then? Do you pick the one that is best? Do you try to get the groups together to come to some consensus?

DR. WINKLER: All of those have actually been part of the work we do. It depends on what they are, but in general our focus is standardization. So multiple measures of the same thing don't meeting that goal. So we're trying to find best in class.

Sometimes, you know, it often is a matter of just choosing one based on the evaluation criteria, and so that's the most common way. We've actually had experience of getting two measure developers to mutually change their measures, to line it up. You know, that may not be the easiest relationship going forward. Who really owns it? Both want to retain credit for owning it, and then the ongoing stewardship may not be the easiest

road to take, but we've done all of those.

So it really just depends on what we're talking about, and outcome measures we'll have to see because a lot of the risk adjustment issues really tend to be unique to that particular measure because it depends on how they do the adjustment and what their study population is for developing, you know, the risk factors and things like that.

So I think we just have to take it as it comes.

CO-CHAIR HOMER: Kathy.

DR. JENKINS: I think I have 14 pediatric registries in my budget right now. It's amazing that it has been a plethora of them, including there's a new pediatric cardiac anesthesia one. There's a new renal one, and so I can get a list of those to you.

Some of them are just all coming. So they're not going to actually have measures yet, and the other one is obviously the subspecialty societies, including you're not

going to find things like pediatric EP, but within each of the subspecialty societies and then there's the one level down of the pediatric subspecialty societies.

DR. McINERNY: Along those lines would be AAP specialty sections that would have all of the subspecialties, and they might know the measure.

CO-CHAIR HOMER: Ellen.

DR. SCHWALENSTOCKER: I'm wondering about some of the maybe less usual customer stuff like Academy Health. You know, could we get to -- they may not be widely used and tested, but you know, maybe more developmental.

DR. WINKLER: The health services researcher.

DR. SCHWALENSTOCKER: Right.

DR. WINKLER: A lot of measures start there.

DR. SCHWALENSTOCKER: And then there's also -- I don't know if this would be

-- this is brainstorming, but AMSPDC, the American Society of Pediatric Department Chairs, or whatever it is.

CO-CHAIR HOMER: Medical School Pediatric Department Chairs, yes. NACHRI itself -- well, you're a member. So that will go to all of the member hospitals, QI departments and QA leads.

DR. SCHWALENSTOCKER: And I've been thinking about this because we've we recently had a really interesting conversation in our council meeting about reaching the right people in children's hospitals around quality issues and discussion of could you identify the one single person in a children's hospital responsible for quality.

Probably not very easily, but what we could do is we could send out our usual call related to this, but ask for it to be broadly disseminated because I'm thinking of the pockets of work that are happening in the clinical departments that we wouldn't normally

reach.

So maybe we could find a way to do that. Especially with more time, I think we could really work on that.

DR. WINKLER: Yes, we should be able to.

DR. DOCHERTY: I was wondering, Reva, would NIH send out -- there's just certain institutions at NIH that actually work on developing different measures. I wondered if they would send out. They have their listserves that it goes out to, and then the other group that does some work in measuring some kinds of medical comes as the Society for Research and Child Development. They would probably send it to their E-mail list as well.

CO-CHAIR HOMER: Bonnie, there's a mental health child outcomes group, isn't there?

DR. ZIMA: Yes. I think a couple of things come to mind, and I think next week when the mental health committee will do some

of its double check on my brainstorming, the State Mental Health Directors Association -- I kind of feel like different states are maybe experimenting and kind of already applying measures on the states, and they might not be well coordinated.

CHADD is a big one for consumer. NAMI, National Alliance for the Mentally Ill. Charlie mentioned Autism Speaks, Bipolar Foundation, and I apologize, but there is a large group advocating for improvement of teen depression and reducing suicide. So some Googling on that.

You're already connected with the American Psychiatric Association quality indicator committee. Rob Plovnick is a friend of yours, and Ginger Anthony would be the contact person for the academy in, I think, child and adolescent psychiatry, and there's at least two committee chairs there that would be potential, maybe three.

But I think I could defer to

Ginger, and Larry Greenhill knows about you, who is the president. So I think you're set.

MS. PARTRIDGE: And, Reva, I assume you communicate regularly with the National Association of State Data Organizations. Denise Love?

DR. WINKLER: Yes, I was going to say they're a very active member. I get my organizations mixed up. Yes, once you said Denise's name, yes, definitely.

MS. PARTRIDGE: Yes, because I know some states do collect certain data.

DR. SCHWALENSTOCKER: How about Family Voices? Could they be a dissemination vehicle or measure?

MS. PARTRIDGE: Yes. They've also done a lot of work around patient experience and involvement of care, and they've got some tested -- I don't know that they're actually what you would call an outcome measure, but -

DR. WINKLER: Another thought, Lee, is the Consumer Council meeting anytime

soon? NCARE's Consumer Council and all of the various folks there.

MS. PARTRIDGE: Well, its chair is Maureen Corry, of course, and for the maternity community, that's the contact.

DR. WINKLER: Yes. It's just that there are some folks in that council that are very -- you know, that have some focus on children.

MS. PARTRIDGE: And of course, we're on that council.

DR. WINKLER: Yes, I know you are. That's why I brought it up.

DR. ZIMA: Do you have a contact in the developmental disabilities services? I'm just thinking again, you know, it gets to be a little idiosyncratic by state, but you know, we're capturing when we talk about development and not achieving milestones, but the huge autism group that may not necessarily be connected with formally health care or Department of Mental Health.

DR. LIEBERTHAL: This may be heresy, but what about the insurance companies?

DR. WINKLER: Yes, they'll get it automatically. They're very active NQF members, and they have used their membership list for us readily, you know. Rebecca blasts on a regular basis.

DR. JENKINS: I assume that all of the pediatric organizations like NACHRI, SAMSA, NICHQ, AHRQ, these groups will automatically be included. Is that true?

DR. WINKLER: Yes, I think so. I mean NACHRI and CHC is a member and you know.

DR. JENKINS: HQ is here.

DR. WINKLER: Yes, we'll get to Charlie. Charlie can't talk. So yes, we do.

CO-CHAIR HOMER: -- surgical site. How do we reach out to the different surgical groups?

DR. CLARKE: Well, I think most of those specialty societies have, you know, a

pediatric or congenital subgroup associated with them. It's usually instead of having surgical group that covers all of the specialties, it's more split up along specialty lines than it is along pediatric lines.

DR. JENKINS: Is this the American College of Surgeons though that has a lot of it?

DR. CLARKE: Well, they have some.

DR. JENKINS: Except for cardiac?

DR. CLARKE: Yes, they have obviously pediatric surgery and pediatric surgery has a society, but that's principally general surgery, and it doesn't cover things like cardiac, neurosurgery, urology, orthopedics. Those are pretty much split up along specialty lines.

DR. JENKINS: Although there is an idea that the new NSQIP program, the National Surgical Quality Improvement Collaborative, the pediatric component has, I thought,

through the American College of Surgeons, made a plan to move into the subspecialty arenas. So whatever their structure is for setting that up would be a good one to tap into.

DR. WINKLER: We certainly have worked with NSQIP before, and actually there's a NSQIP measure in the main outcome group to be evaluated.

DR. ZIMA: Two more issues. Neurology is not well represented here, and I'm not sure in your database, pediatric neurology, Epilepsy Foundation. I'm thinking again about people who have to care for mental health and developmental delays in children.

Also education. I mean, we talked a lot about school performance. I don't know whether special ed. advocates -- I mean, we're getting into kind of waters, but I would imagine the huge special ed. community advocating for children would go along nicely with some of your outcomes.

CO-CHAIR WEISS: And, Reva, of

course, you can count on us to disseminate --

DR. WINKLER: Thank you.

CO-CHAIR WEISS: -- whatever you need disseminated throughout the country.

DR. LIEBERTHAL: -- and allergists included in your list?

DR. WINKLER: They are for the most part. Those societies are members, and so to the degree that the person, our contact that we send to and each association may have two or three that would get the message, would feel, you know, would embrace and maybe send it on to the appropriate, more pediatrically focused group, you know, sort of is always a question.

So if there are any specific people you are thinking about in the emergency care world or the allergy world, you know, we can be more specific in our targeting.

Okay. If you've got thoughts along that line, don't hesitate to share, but

at the same time, you know, this is one of the benefits of the electronic world, and you know, E-mail files readily and freely throughout the world.

So we do need to work as a team to get that message out. So we hope that if there are measures out there, that they can come into the project. We really do have to get the word out and get the appropriate people notified.

So okay. In terms of the last topic --

CO-CHAIR HOMER: Kathy. Kathy has one more.

DR. WINKLER: I'm sorry.

DR. JENKINS: No, actually I was going to raise something else, but maybe it was your last topic.

I also thought that it would be an important component of this work to look at that other several hundred NQF endorsed measures for that either relevance to the

pediatric population or, as importantly, lack of relevance to the pediatric population.

How is that activity going to fit in?

DR. WINKLER: Not sure at this point. I think we have to talk a little bit more internally about that. That's not exactly a minimal undertaking, and I think it would take a certain amount of staff work up front because some things are real clearly, you know, we can eliminate those off the list.

Because having looked through our list of 500-plus measures, for any number of reasons, it's a fairly daunting list to run. But I think that we can certainly think about it a little bit more in terms of how it might feed into this project.

So I don't have a real good answer for you at the moment, but certainly something to put on the agenda for us to consider.

DR. JENKINS: I think it's very important, and the only thing I'd say is sort

of a divide and conquer strategy often works well.

DR. WINKLER: All right. One thing Charlie was asking me about, and that was all the conversation we had about framework. Now, where in the world did it go? It's another one of those.

What I did was start talking about some of the elements you guys had talked about yesterday in terms of how might we look at a framework, and I took the categories on the left-hand column, which was the bullet list, you know, modified, and we can certainly modify it, and then I took the age ranges that Charlie, you know, offered up, and I popped in the outcome measures from, you know, page 10 to just show how this might work.

And we can have conversations about, you know, if I put them in the right box or not, but you can see that by doing this kind of thing, we can see where gaps are. We can see where we have measures. We can see,

you know, certainly the desirably areas.

The biggest question I had was, you know, which ones do we array against each other. So this is age against, you know, our types of outcome measures, but then I also took it to another group, and I went to, you know, the IOM Aims as well as the NPP goals. There's a little bit of overlap and not.

So you can start to see where some of these come in. I rated against the bullets, but I also thought, well maybe these need to be arrayed against the ages. Right. Well, I'm trying to do something that's multi-dimensional in a two-dimensional space.

So you know, this might be a useful one. I didn't plug them in. I just was sort of building the concept so that having measures for all of these different periods of a child's life and we would want something in each of the boxes probably at each of the elements.

So this is one that you think is

valuable? Okay.

DR. JENKINS: I would have thought the hierarchy is the Institute of Medicine aims and then for each of the acute, chronic and what's the next one? Prevention, and then the ages because some of them will be applicable across all conditions and all ages.

DR. WINKLER: Yes, right.

DR. JENKINS: And some of them obviously won't.

DR. WINKLER: Yes. In building this I had exactly those questions, and you know, I was just trying to kind of get something down for you to react to. So the question is it sounds -- okay. So I took the bullets against both, you know, ages, the NPP, IOM goals, and then the acute, chronic, preventive construct.

But the question is: do those go better against ages? Or both?

CO-CHAIR HOMER: I think you'll need multiple. I think this one is useful.

I think the age against the STEEP is also useful. My guess is you're going to need to do this in a database.

DR. WINKLER: Oh, absolutely.

CO-CHAIR HOMER: To make sure you have characteristics of each and then look in multiple --

DR. WINKLER: Exactly, exactly. I was just trying to think about what are the things -- these are the issues you brought up, and this is very rudimentary, but how would you like to see them related to one another?

CO-CHAIR WEISS: I'd also like to see, going back to David's point, in patient/out patient.

DR. WINKLER: Okay. And that would be important to compare against what, age?

DR. JENKINS: It's not compare against age. It's that a measure may be pertinent across the spectrum of ages. So a measurement may only be pertinent for specific

age groups.

DR. WINKLER: Right, and that's why I'm --

DR. JENKINS: So weight to STDs is not pertinent for infants.

DR. WINKLER: Right.

DR. JENKINS: Or infant mortality is not pertinent for adolescents.

DR. McINERNY: But I think in patients certainly and out patients, both you would want to run against the IOM six goals.

DR. WINKLER: Versus the IOM, okay. I can do that. I can drop that. I can put in patient/out patient down here and drop it against this one.

CO-CHAIR HOMER: And without being too much of a splitter, the comparable table that I'm putting together for the other NQF project has out patient broken down into, you know, basically specialty, emergency department, and primary care. So I think that's a reasonable way to frame that.

DR. WINKLER: Okay.

DR. PERSAUD: Are the NPP the IOM priorities or is that different?

DR. WINKLER: They are different, but there's a lot of overlap.

DR. PERSAUD: There's overlap?

DR. WINKLER: Line 3, effective, safe, timely. Those are the IOM aims, and then the NPP I've got in the line above it. So safety, you know, patient-family engagement, overuse, but the population health, you know, either goes over all of them or it's its own thing, and the same with care coordination. It kind of goes with all of them.

DR. PERSAUD: Okay.

DR. WINKLER: So, you know, I'm having trouble depicting some of these.

DR. PERSAUD: What might be nice in the ultimate document, however we choose to overlay them, is to have bullet asterisks that tell us where a construct fits, whose IOM,

whose --

DR. WINKLER: Oh, yes, yes. Okay.

So anyway, these are the kinds of things that help us do an analysis of what we've got already endorsed, where the new measures may fit if we do, and hopefully they're going to plug some holes, and then clearly the empty spaces provide the gaps.

Now, some of these actually don't make a lot of sense, some combinations, and I think some of them will be very, very like, whoa, you've got nothing in this and it's highly important. And so I think it will be an interesting thing to do to kind of come up with an analysis of desirable measures that we don't have, either not endorsed yet or have come into the project, to create that list of this is the stuff that needs to be developed out there, and this is just sort of trying to draft up a tool to help us figure what those things are.

DR. JENKINS: The other thing,

you'll have to filter the tool in terms of the lends of outcomes because some of them, like I'm thinking overuse, under use, may actually not fit perfectly with the patient outcomes.

DR. WINKLER: Right, exactly.

DR. JENKINS: So as nice as the framework is. So to filter it down to the core about child health outcomes will be very important.

DR. WINKLER: Like I say, this is sort of a first pass, you know, laid down in two dimensions because I wouldn't think of any other way to do it, to share it with you all, but just as a starting point, if you'd like I'll be happy to share it, but ideas from all of you, how do we, you know, make this more appropriate for child health in its next iteration, and I envision this to be somewhat iterative or definitely iterative to see if we can ultimately come up with something that's really a tool to help us understand what we have and what we need.

So, again, this is one of those be happy to share it with you and feel free to, you know, come up with all sorts of great ideas. I'm mining your brains.

DR. CLARKE: One thing that occurred to me, you mentioned yesterday about sort of blurring the 18-year cutoff, and I'm wondering if we ought to have a group of young adults. I know that at our hospital, Children's Hospital, patients with congenital heart disease are treated usually up to around age 30.

DR. WINKLER: Yes, a lot of those.

DR. CLARKE: And some other subspecialties do the same thing.

DR. WINKLER: Yes, a lot of the congenital stuff.

Tom, did you have a question here?

DR. McINERNY: Well, I'd just make a side bet we're going to have more blanks than filled in spaces.

DR. WINKLER: Well, and I think

that's reflective of the state and just some of the frustration that a lot of folks in the child health world have expressed, that there just aren't a lot of measures for children, and we're not focusing -- you know, the collective "we" -- not focusing on children enough, and that sort of thing. So yes.

But sometimes doing this kind of an analysis brings it very clear, sort of crystal clear. There's just a lot of work to be done, and a lot of different kinds of measures than the few that are -- they all tend to cluster in the usual pipes, and are not as expansive and cover a lot of the areas that you all identified, and making that explicit, getting that word out, you know, talking that these are the desirable things, not just, you know, these few narrow outcomes we're used to seeing. It is really where we want to go to have a much more rich measurement portfolio for kids.

DR. ZIMA: Yes, it's interesting

because we came in thinking we knew our age groups, and I think this last comment would make me feel like my working table would say young adulthood, greater than/equal to 18 to, and I'm not sure what that last number should be.

CO-CHAIR WEISS: Well, I don't think there's a right number, but I think it's important that this group come to closure around what we think is a reasonable number.

PARTICIPANT: Twenty-one.

CO-CHAIR WEISS: Now, are we going to go with the AAP, 21, or are we going to go with what the Medicaid and CHIP programs consider to be children since we're dealing with CMS as the funder? Are we going with what the providers are doing out there, which is a more expansive definition?

I just think we need to have a working understanding and have that reflected in the materials that go out.

DR. ZIMA: It's a big issue in

mental health because when I hear about your patients, I start thinking about all of our psychotic autistic children that would not be appropriate for schizophrenia clinic, and they still have parents involved, and they're 22 years old. They're very special, you know, or DDs.

CO-CHAIR WEISS: Yes.

DR. WINKLER: And one of the issues, I think, this speaks from just a purely measurement perspective. The issue around needing to harmonize and keep things consistent just for the ease and reduction of burden of measurement and not confusing some of the needs of just the technical needs of measurement versus what's appropriate in the actual care of patients. And measurement is tools that reflect it. So you may not capture the young adults that fall into it, I mean, or it may need their own set of targets rather than trying to cover all things with all measures.

But I do think that it will be confusing in the audience if we have measures that have a mixture of age endpoints. I'm not sure we will have fostered the standardization that's a priority for us.

There may be specific exceptions that you'll want, and if you do, you know, say so, why, and then I think that's reasonable. But, you know, some of them end at 15 and some of them end at 18 and some of them end at 21.

DR. ZIMA: It might be okay to simply share with the reader this dilemma, and that, you know, based on different funders, adulthood starts on different ages.

DR. WINKLER: right.

DR. ZIMA: And that for purpose of this, we specified 21 or 25 or whatever, with the acknowledgment that we're a work in progress.

CO-CHAIR WEISS: Well, let me also put another complication on the table, and that is going to the population-wide issues.

The data sets that the Census Bureau, for example, uses cut off at 17. When the child turns 18, they're no longer captured in that increment.

CO-CHAIR HOMER: Kathy, you had one?

DR. JENKINS: Yes, I think this is going to be very important, and I'm just going to personally state my opinion that with all due respect to data harmonization, I think that validity actually trumps everything, and sometimes when there is an explicit call for harmonization across age groups, in particular, there can definitely be a loss of validity.

I mean, my example in what I know best, the original adult databases were all children were lumped together and then children by age in years, and then there's the harmonization around less than three months where the data shows that there's a marked increase in mortality in the infants in the

first month of life, and anything that doesn't capture that difference between a one month old, sick, critically ill at birth, from a child who goes home for a while and comes back, misses a marked validity problem.

And so that's also going to be attention. So when measures come forward, I think that that tension between harmonization around the overall scope of the project or the age brackets, when there are specific validity issues, I'm personally going to feel that you have to make exceptions for that or we'll really throw the baby out with the bath water.

And I think that's how people disagree, because they need a harmonization expert.

DR. WINKLER: And that's exactly the issue around explaining why if it's not aligned, and if there's a very good reasons for it that should be fine. It's when it seems more arbitrary than not that, you know, this group thinks it's this and this group

thinks it's this, you know. There isn't anything that really substantiates one versus the other. It does sort of drive the world out there crazy when there doesn't seem to be a very good and valid reason for what's included.

CO-CHAIR HOMER: Do we need to make this decision now?

DR. WINKLER: No, no. I think it's one of those be alert sort of. Well, I guess maybe perhaps in the call for measures, do we want to put anything in in terms of their definition of child? And age, I think, is sort of a defining thing of child, or do we leave it open at this point?

CO-CHAIR HOMER: I think really the critical question on the table is 18 versus 21, you know, on the other end, and your comment on CMS is that Medicaid coverage goes through 18 or through 17 or --

MS. PARTRIDGE: Medicaid can go up to 21, state option.

CO-CHAIR HOMER: Well, then I would suggest we speak up to 21.

CO-CHAIR WEISS: It's mandatory through 18 and then option to 21.

CO-CHAIR HOMER: I would suggest age 21 because the AP like 21. It's a Medicaid option up to 21. We won't annoy anybody. I guess the only problem is some of the public health data cuts at 18, but there I think we could put caveats around and do that.

DR. WINKLER: So it's less than 21, right? Once they turn 21 they turn into something else, otherwise known as an adult.

CO-CHAIR HOMER: I mean I think we will --

CO-CHAIR WEISS: To age 21.

DR. WINKLER: Yes, so it does include 20. So that's fine.

CO-CHAIR HOMER: And I think we will probably want to end up making some recommendation down the line that NQF get

funded to do measures on the young adult transition related issues both for the biologic reasons that we're talking about of kids with congenital disease, plus the insurance related issues.

DR. JENKINS: Could we make sure then that the main group is starting at age 21?

DR. WINKLER: Now, that gets to be real interesting because most of the measures tend to be specked at 18, and they didn't specifically look at it with an age, but you're right. That gets to be real interesting.

DR. JENKINS: We've had this even with the registries, you know. Where does one end and where does the next one begin? And are you asking people to double the report and all this stuff.

CO-CHAIR HOMER: How would you resolve it?

DR. JENKINS: I don't have a good

answer, but I think that what should happen is that wherever one lets off, the next one should generally start, unless, back to my prior point, there's a validity reason which at times there are.

The practical reasons are different. If people only have data in certain age ranges, that's where their data source starts for whatever they're putting forward, but with the exception of validity reasons, I think one should end where the next one begins so that the whole population is covered.

DR. ZIMA: This discussion, I think, raises something that I anticipate is going to happen for you, and that is sort of bringing in child and then bringing in the mental health group. It's going to take, okay, what lessons were sort of learned that are going to focus the revision of the work that's already happened on the main committee, the issue to age, the issue of goals of

caregivers, and I think the concept of transitions.

We didn't talk about other transitions in adulthood like employment or decreased divorce. So I think as your work group goes on that there might be another additional feedback to the main committee after you processed what's happening --

DR. WINKLER: Sure.

DR. ZIMA: -- the next two weeks for you.

DR. WINKLER: All right.

CO-CHAIR HOMER: I also want to echo, I think, Kathy's earlier point. My guess is from the outcome measures for your grid here, we're going to convince them to -- it's just a few, you know, probably something like mortality and morbidity, iatrogenic or hospital acquired, you know, and population health.

I think it makes sense for us to put this all out there in detail so people

know what to respond to, but when we sort of put it into a grid, I think we'll shrink it down to three or four categories.

DR. WINKLER: Work in progress. So all of your thoughts are good. You know, we've got several documents that we generated to share with you, and so we'll kind of package them up and send them to you, and again, feel free to share any of your thoughts.

The last thing I wanted to go over was the major evaluation criteria.

Do you have your PDF in here, your PDF document? Where is it? Oh, this is it. Okay.

This from your PDF packet that was sent to you, and I'm going to go down to page -- I'm not sure where it is. I'll know it when I see it, so that you've got it to follow along -- the major evaluation criteria, and I don't want to belabor this, but I do want to point out to you some of the issues because

some of your questions have come up around this, and I do just want to reassure you that the criteria are rather detailed and basically comprehensive.

And so we're starting on page -- after 17. So, yes, it's its own document. So, Jane, if you're still with us, we're on -- it starts following page 17 in your package of materials, the evaluation criteria.

We had talked about the conditions of four submissions. So that's kind of administrative.

The first major criteria that's sort of discussed -- why am I doing this? Thank you, Charlie. The criteria, four main criteria we mentioned before: importance to measuring report, scientific acceptability to measure properties, usability and feasibility.

So I just wanted to point out to you that under each of those criteria we have a definition for what we mean by the main criteria, the importance to measure report,

the extent to which the measure is specific. The measure focused important in making significant gains in health care quality as defined by the IOMA, and improving health outcomes for a specific high impact aspect of health care.

So it's not just is it important. There are lots of things that are important, but we're trying to focus in on things that are going to have large impacts.

This particular criteria has three sub-criteria. One is it addresses a national health goal or priority from NPP, or a demonstrated high impact, large numbers, high severity, high cost. We've actually seen some very, very narrowly focused measures that will be captured, this tiny, tiny, aside from the technical problems, small denominators. The utility of a measure like that in driving significant gains in health care is questionable. So that's the first one.

The second one is there is a

demonstration of quality problems and opportunity for improvement. We've had measures submitted to us where the current performance is 98 percent with no variation.

Good, applause, and move on because it doesn't really help us promote the change we're looking for.

CO-CHAIR HOMER: Without belaboring that first one, it's going to be tricky for us.

DR. WINKLER: Absolutely.

CO-CHAIR HOMER: So for any of the pediatric subspecialty issues, even the relative -- something like sickle cell or something like that, you know. Compared to congestive heart failure, it's going to look like ho-hum. So we're going to have to --

DR. WINKLER: Well, --

CO-CHAIR HOMER: -- come up with criteria around that.

DR. WINKLER: -- but I would say because we've narrowed your focus to children,

I think there are high impact areas more so than others within children. We don't have to look at congestive heart failure. We don't need to look at the Medicare population. We're going to look at kids.

So I think that's a perfectly reasonable thing. What's high impact within, talking about kids. I don't think we need to -- otherwise, you know, we're going to marginalize children forever.

But the demonstration of a true quality problem is an important one, and then the measure focus, either it's an outcome measure -- being an outcome measure gets you a point. I mean, you pass that criteria or there's a relationship that links it with an outcome, and this is true for intermediate outcomes, too. I mean, you know, blood pressure targets should be, you know, associated with long-term reduction in morbidity and mortality, et cetera, et cetera, et cetera.

But while this is really a critical aspects, getting the evidence right, going back, what is the quality of the evidence is really an important part of the evaluation for process measures, less so for outcome measures because outcomes are really sort of the end result that people are interested in.

Certainly we do want to look at whatever evidence is available, but it will be a little bit of a lesser issue for this project.

Realize that that it's a threshold criteria. If you're not important to measure and report, i.e., it's not -- what we're going to get from it isn't worth the investment in data collection and crunching, the burden, then you know, stop. It can be highly valid, but not terribly important.

Scientific validity or acceptability of the measure has multiple sub-bullets. One is the measure is well defined

and precisely specified. That's the standardization. You can't expect different groups to give you comparable results if they don't start with the same very precise specification. So that's an important thing to look at.

Reliability testing, validity testing, as we mentioned before, these are kind of open ended questions. Did you test the validity? How did you do it and what did you find are sort of the sub-questions in the submission form, which I'll show you briefly.

And so the same with validity testing. Clinically necessary measure exclusions. One of the significant discussions that's happened over the last few years in major specification is sometimes you'll see measures with lots and lots of exclusions, clinically appropriate, but they contribute very, very little to the actual measure results, and collecting that data for that, you know, tiny exclusion is very costly

and burdensome, and it doesn't change the actual measure results very much.

So the idea that we're focusing in on the exclusions that actually impact the result as opposed to absolutely everything listed in, you know, a textbook --

DR. RAO: So, Reva, just to interrupt you, how would you handle that situation? Would you just take out the exclusions or --

DR. WINKLER: Well, I think, you know, the first thing we ask the measure developers is why do you include it. What's it getting for you? What's the mileage out of it? And then perhaps see how amenable they are to like, you know, what happens if you get rid of them. You know, what happens if those are eliminated?

I think each one has to be taken individually and have that conversation with the measure developer. I don't think you can make some blanket statements because it

depends on how they handle different things, and there may be good reasons for it. But in general, the idea is keeping the measurement burden of data collection reasonable and important as opposed to just making it a laundry list that may improve the face validity for clinicians, but at the same time just doesn't impact the measure.

This is the difference between care and measurement, and it has come up more than a few times. It particularly comes up when you have a measure that can otherwise be done by, say, electronic data or administrative data, but you have to go to the chart to pluck out the exclusions. You've taken a measure that's relatively feasible and low burden into something that's almost impossible to do. And if you need to do that, there should be a really good reason for it because it does change the feasibility issues.

So that has become just a significant conversation in NQF land.

DR. JENKINS: Reva, can I just ask because, you know, preaching to the choir, I completely agree with you there, although the face validity issue is huge for individual docs who don't want to have one patient who is the exception somehow counted against them.

Has NQF added in the locus of the appropriate use of the measure in terms of numbers of cases or class or larger group, let's say, a plan, a population, an entire hospital?

DR. WINKLER: Not --

DR. JENKINS: To try to weather that storm?

DR. WINKLER: Not explicitly. I mean, we tend to have so little control that making the recommendations -- and sometimes there are about responsible use of the measures with appropriate statistical validity and significance, usually is a tag to almost any of our reports, but again, you know, yes, it's more in the use kind of element of it.

DR. McINERNY: One particular example comes to mind, and when you apply the measure, the pediatricians and others would be concerned for immunizations. Your immunization rates would be affected by the number of parents who were vaccine refusers.

And so what do you do with that exclusion?

DR. WINKLER: Let me -- not wanting to get into an entirely large conversation about a project that we did on harmonization and immunization measures and the way measures are specified.

And actually what they've come down to is stratifying the numerator such that the numerator includes patients who were counseled but refused, patients who got it -- somehow I want to say there was a third category, but I can't figure out what it was -- and so you have a way of accounting for everybody, and from that you're able to figure out what the actual immunization rate is, who

actually got it as well as factor in the other.

And so the measure kind of addresses all of those issues and concerns in the way it is constructed, and that sort of then establishes what we call our standard specification for an immunization measure, and all immunization measures that come in are judged against that standard.

So you're right. Those issues have been sort of hammered out along the way.

This is what I think David was asking about, the 2E for outcome measures and other measures when indicated. An evidence-based risk adjustment strategy is specified and is based on patient clinical factors, blah, blah, blah, blah, blah.

So this is a definite evaluation criteria and then or rationale or data to support no risk adjustment is needed. Well, maybe there is some reason.

And then the data analysis

demonstrates the methods for scoring. Okay. You crunch the data. What does it look like when it comes out?

If there are multiple data sources allowed as we've seen measures, well, there's the HR version, and there is the chart extraction version, and then there is the admin data version. It's like are those comparable so that if someone chose to do it one way versus another, at the end of the day are the results comparable. And so not just saying, oh, yes, any way is fine.

And then how are disparities handled? And if not, how do you plan on handling them because it's an important issue?

The third one is usability, and the three criteria, this is the extent to which the audiences understand results and can do something with them and are likely to find them useful.

So this is one where we don't get lots and lots of information, but when we do,

it's golden, and that's if there's any ability to demonstrate meaningful information for the audiences either through public reporting or informing quality improvement.

So like I say, we don't get a lot of the really nice testing that everybody would love to say does this work for the intended audiences, but it's certainly one of the criteria.

This is where harmonization comes in, the major spec to harmonize with other measures because measures that are very unaligned are hard for implementers to use them as a group. What we've seen is if you have a collection of asthma measures, if they all define the denominator slightly differently or the age range slightly differently, then what they do is they pick and choose to make it as easy to implement as possible, and they won't implement the full group. So the harmonization makes them more usable in the implementation world.

And then review of our existing endorsed measures to be sure we're just not adding another one of the same old thing. We're still struggling with trying to figure out how that evaluation against an endorsed measure because, frankly, a new measure may be better, and if it is, that's fine and the feedback goes back on the one that's endorsed in terms of its maintenance review or maybe it needs to be either morph or die or something.

So realizing this was sort of a living, breathing kind of thing, and then feasibility, the extent to which the data is readily available to collect, to do the measures without undue burden, and we're trying to hope that pushing toward data collection concurrent with care delivery so it's not an extra step, but it's just part and parcel of it, I mean, that's the vision of the HR. But you may have other clinical systems that may collect data. Case management systems do it, all sorts of things.

And the data elements are electronic. You know, that's far easier than any chart abstraction, and if not, you know, do you have a near term path to get there? The idea we don't want to encourage people to keep creating measures based on chart objection. It's not going to be, you know, useful for pretty much anybody.

Our experience is those measures don't tend to get used anyway. So they get created and not used. Oh, boy, what have we done?

So, again, the feasibility, the exclusions not requiring any additional data source, and ability to audit the data is an important one, and the fact that it can be implemented.

Some measures that are already in use have a certain step up here. I mean, they've demonstrated some feasibility, and they've demonstrated something about how the measure performs.

So those are the criteria. In terms of how we're going to implement this for you, if you continue on what I'm going to show you is just -- we just gave this to you as an example. This is the pediatric cardiac surgery.

What you will get for each measure for your evaluation is we will embed the responses from the measure developer in this evaluation form and what they answered and then your ability to evaluate it over on the side based on their information.

So we're going to lead you through the evaluation criteria step by step. Given the answer to the question, the measure developer has responded to provide us the information for that, for you to be able to do your evaluation. And so you'll just use this.

The actual Word documents we give you are a bit interactive, and these bubbles don't come up on the side. They'll actually come up if you point to it, and there will be

a bubble that will remind you what the whole criteria is. So you won't have to toggle between documents or it won't be small size.

So it's an interactive document. We've got a couple of folks on the staff who love doing all of this technical stuff. So it's grand for the rest of us who haven't a clue. We just watch in amazement.

But so all of this gets embedded, and that's why the electronic submission, you know, we've got it electronically. We're able to put it in this and make this a very interactive kind of thing.

So this is what you're going to receive once we have measures to evaluate. Again, numbers will determine the exact plan, but we typically separate the committee into like either groups or if it's more like a handful of primary and secondary reviewer who will take the lead for the discussion on each one. It certainly will try and match it up if you have a clinical specialty area of

expertise.

If we have things that seem to need expertise that we don't have, we'll find an advisor to help out to answer some of the questions. So you know, we'll work with you.

Like I say, once we know how many measures we've got, we'll be back with you with a more detailed work plan of exactly how we're going to tackle them. But this is going to be your primary tool for doing the evaluation.

Both Lee and Charlie have watched NQF go through evolutions of these. Back in Lee's day, in the first project I did we had evaluation forms. There were tables, and Charlie carried around binders that were five inches deep to do ambulatory care. So this is our way of getting past a lot of the kill the trees and as well as keep things electronic. Because actually once we finalize things for you, when we get the answers on a final one, we can backfill this into the electronic

system and we then have the database of not only what they submitted, but your evaluation of it and everything builds from there they tell me.

CO-CHAIR HOMER: But it's basically, if I understand it correctly, we're the ones who actually are making the decision about --

DR. WINKLER: You bet.

CO-CHAIR HOMER: -- for example, is it high impact.

DR. WINKLER: Correct.

CO-CHAIR HOMER: So we have the criteria and we have the measure. So obviously the developer will say it's high impact and we'll look at the prevalence or the impact and make our own judgment about that.

DR. WINKLER: Correct.

CO-CHAIR HOMER: So that's basically our work.

DR. WINKLER: Exactly.

CO-CHAIR HOMER: And then we'll be

discussing within this group basically whether the whole groups agrees with, for example, the primary and secondly reviewer.

DR. WINKLER: Exactly. That's going to be the primary agenda for your April two-day meeting, is we will be, you know, discussing each of these measures, and for those of you who have done it, these can be very intense meetings. Again, it all depends on how many measures we're talking about.

You'll all have the opportunity to lead the discussion around whatever measure you get the lead for, but it will be a group effort. I mean, everyone kind of comes to the conclusion the final evaluation of, you know, is it important; is it scientifically acceptable; is it usable; is it feasible; and then ultimately what is your recommendation for endorsement. Yes or no, should it be recommended for endorsement or not?

And that's the decision making that this committee is charged with. So we're

trying to give you all the tools and information you need to get there.

DR. ZIMA: Question: are there two rounds of ratings, two rounds of expert ratings or just one during the face-to-face?

DR. WINKLER: Like I say, depending on the number of measures we may want to have some preliminary phone calls and do some preliminary kinds of things, or if there -- it depends. I've done it any number of ways.

We may break you into little groups that you can talk preliminarily among, you know, three or four of you to kind of get some sense of it and bring that to the whole committee. There are a variety of ways of doing it.

DR. ZIMA: I'm thinking in terms of the RAND method that was used in Beth McGlynn's study.

DR. WINKLER: From Adelphi, from out of Adelphi?

DR. ZIMA: Adelphi, you know, that before we can --

DR. WINKLER: Not typically.

DR. ZIMA: You know, there's a few that everybody agrees and you know ahead of time you are the outlier.

DR. WINKLER: Right.

DR. ZIMA: Then you start your discussion --

DR. WINKLER: Well, one of the requirements is that each one get its day in -- you know, on the agenda so that, one, it's recorded in the transcript. The evaluation is agreed upon by everyone, but you're right. Some of them can go quickly, but some not.

But again, if we have a large number of measures, we may want to do some preliminary things to let a few of you, you know, kind of have a chance to talk among yourselves, think about it, because there are often questions. The measure developers are involved in those conversations. So you can

ask them, you know. Is this -- what's this? Can you do this? Why didn't you do that? Whatever, so that you have an opportunity to really feel comfortable that your evaluation is based on solid information.

Like I say, if we've only got six measures in two days we can do it here. If we've got -- don't faint, Jane -- 60 measures, I'll break them down somehow, you know, and do some preliminary work because there is no way we can do 60 measures de novo in a two-day meeting. Been there, done that. It doesn't work real well.

So we've got experience with dealing with various numbers of measures and how to break the work down for the group, and like I said, since right now it's an open ended question on volume, we'll have to wait to see exactly the method we'll choose to do it.

MS. PARTRIDGE: Reva, I'm just going to put in a plea that we not do

something in which we break down into small groups and discuss a group of measures and then come back to the whole group because when we did that with the perinatal, if you remember, it meant that half of the group had none of the benefit of the discussion.

I understand when you've got a big volume it's very, very tricky, but I think for the benefit of the group it's important to be able to hear the richness of the discussion sometimes on measures that weren't assigned to your little group.

DR. WINKLER: Okay.

MS. PARTRIDGE: Because I think we all felt when we had to vote on the measures we hadn't heard about, that it was not very comfortable.

DR. SCHWALENSTOCKER: Just a question really, and it goes to your question, Charlie, earlier about impact of the measure. So I'm just trying to get a sense of what we're going to see from the developer. Does

the developer also kind of make a case for why they think the measure should have impact or does have impact?

DR. WINKLER: Yes, they are asked to, and you know, some of them are very detailed and some less so. It just kind of depends what they choose to do, but for the most part they're trying to make a case for it.

DR. JENKINS: I was just going to make a plea. Maybe you were going to do this anyway, Reva, but you are going to filter out the structure and process measures so that we don't start by debating that first, especially if there's a large volume?

DR. WINKLER: Yes. I mean, we should not get them because we're not asking for them. That doesn't mean they won't. I agree with you, but yes, I will probably, you know, do that with the blessing of the co-chairs, you know. Just I think these are process measures. I don't think they qualify.

Do you agree?

Perhaps, and if there's a controversy we can share with everybody and say, "What do you think? Yes or no? In or out?" kind of thing. The ones that are pretty obvious I think we can do.

MS. PARTRIDGE: And similarly, you'll screen out ones that clearly don't meet at least half of the criteria.

DR. WINKLER: Well, again, if we end up with large volumes, that certainly would be one way of sorting them out, and again, ultimately that decision is yours, but we can help kind of say, "These don't meet the this criteria. Is it okay if we put them aside and go no further?" and you would have to do that.

But, yes, I think that's quite reasonable.

DR. LIEBERTHAL: This is a follow-up on what Ellen asked. Are we going to be using objective criteria for impact? And I'll

give you an example. Cystic fibrosis has very good outcome measures. If you run a cystic fibrosis center, it has very high impact, but I don't know in general terms if 30,000 patients across the country is high impact.

DR. WINKLER: Right. I think ultimately that will be your decision. I think the idea that keep it within the child world; don't worry about the high volumes of Medicare patients. Just ignore them.

And then I think it will be up to you to decide whether there is value in that, and in the information provided. Again, this is where differences of opinion -- it will be a committee decision how you meet that criteria or not, realizing not everybody is going to agree with you whichever way you go.

So there are no absolutes for any of these criteria. Certainly the best measures will score highly on all of the criteria and the not so good measures will not score well on, you know, several criteria.

But there is no absolute, you know, threshold. You don't have to have a certain score to pass or anything at this point. It has not been -- a grading system like that has not yet been developed.

DR. McINERNY: You know, I do think though that we should keep in mind there are many customers, and some of the customers are very large, such as CMS, and some would be somewhat small, such as the record of CF centers.

But all of them would probably be looking for measures, particularly now that we're in the maintenance of certification, and so the specialists are going to want to say, "Oh, my goodness, what can I do for MOC? Ah, here's some outcome measures available for my specialty, and we could do a quality improvement project looking at those outcome measures and see if we can make some changes."

And while I have the floor, I just want to say that both usability and

feasibility are probably functions somewhat of the eye of the beholder. Fortunately though we have different kinds of beholders here in the room, but we should also think about maybe some other beholders that aren't in the room and try and think about their viewpoint as well.

CO-CHAIR HOMER: My experience has been that those are the two fuzziest criteria that become challenging, and it is interesting because we don't have on the steering committee as we typically do, I don't think, you know, major insurers, major representatives of the large integrated delivery systems, things like that.

DR. ZIMA: Well, it's interesting. I actually when we did our state study, the people that had the final say on feasibility actually were QA nurses, and so anything that initially passed, if it didn't pass the QA nurse ratings for feasibility, it didn't matter what the expert panel felt.

For the medical records, and this was a medical record study, but that--

DR. RAO: Reva, how do we deal with missing information, a measure that's pretty good overall, but they have just not completed the forms or there's one or two pieces of missing information there?

DR. WINKLER: I mean, like I say, we invite the measure developers to any meetings you have where you've discussing it so that they're available for you to ask questions.

At some point I will tell you what we're doing right now is we scan them as soon as they come in. If it looks like they put the information in the wrong spot or they left it blank or something, we circle back with them and say, "Hey, you know, are you sure you want to leave this blank?" because blank, we're assuming there is no information. You've got nothing to contribute. I'm not sure that's going to help your case.

We might give -- you know, each project has been a little bit different. For the most part we try and give them an opportunity to spiff them up a bit, but otherwise they just have to fly the way they submit them. If there's no information, I think you have to assume there is no information, and if it's an unknown, it's an unknown for that criteria, and you'll have to see how you want to weigh that in relationship to all of the rest. So that's where you are.

DR. JENKINS: Reva, at the end of the day is it the consensus of this group or is it a vote of the group or how does that work?

DR. WINKLER: There's actually a vote that forms the basis of the consensus. Consensus is not unanimity. It's allowing everyone to have their say and voting, and then it's sort of the group and majority is generally how we base the recommendations.

CO-CHAIR HOMER: But then what

happens after this? If we think -- actually, whether we say yes or no, that gets out for public comment; isn't that right?

So the general membership can either --

DR. WINKLER: Opine.

CO-CHAIR HOMER: -- can opine. Can they overrule our negative? So if we don't say something is worthwhile, they can opine. If we do recommend it and the overall membership says --

DR. WINKLER: They have got two avenues then. A couple of things. The comment is their sort of assistance to you as their representatives saying, "We don't like this." But again, depending on the number of people, you may have one outlier who says something and everybody else thinks it's grand. I mean, you kind of have to weigh it.

But that's why the comments come back from the steering committee, for you to look at and say maybe we should change one of

our recommendations based on the comments, or you know, yes, we considered all of these things and we still, you know, have included them in our deliberations and, you know, we stick with our recommendation.

So major recommendations have definitely been changed by comment, but it's your decision. I mean, that's why you are the steering committee. It's up to you.

But you're getting input from a variety of places, and it's sort of a dialogue, and that's the whole point, and you do want to take the input seriously.

In terms of measures recommended, ultimately when they go to vote they could be voted down. Memberships could say, "No, no, no," and that would kill it. That happens extremely rarely, but it has happened.

And then ultimately it goes to the CSAC. If they feel that, you know, we were way out in left field somewhere, you know, and the membership didn't pay any attention, they

could kind of say, "What are you doing?" you know, and want to have an interaction over what's happening because they're acting on behalf of the board before it goes for final endorsement.

So there are a couple of consensus standards, approval committee. It's a subcommittee of the board. The board's function for endorsement, because it is the board of directors who grants the endorsement, they have a subcommittee that they've assigned that task to because, frankly, it's a big task. They meet monthly, and they have a lot of work to do, frankly, and the board just couldn't handle it anymore. So they created a group to take on that function on their behalf.

So there are several opportunities for dialogue back and forth to refine this so that at the end of the day this is a product from NQF as an organization of organizations, and everybody having an opportunity to

participate. Even if they choose not to, they have the opportunity to participate and weigh in.

DR. LIEBERTHAL: Once it goes through the whole NQF process and becomes a standard approved by NQF, organizations can use these and choose to use them or not. What is their incentive to use them?

Because I'm like NCQA, that once they approve something and once they make it a HEDIS specification, everybody jumps and uses it.

DR. WINKLER: There's a variety of incentives, if you will. The biggest one is when it gets adopted by somebody like CMS, you know. That sort of is pretty much everyone's incentive.

And, again, as I mentioned, you know, adoption by the federal government, but adoption by some states, some states are very much more proactive in doing measurement than others.

Also, there are a lot of purchaser groups that look to NQF. In fact, for those of you from New York, the New York Attorney General's Office had brokered an agreement with health plans about doctor report cards that they would only be using measures endorsed by NQF or a similar kind of body, and there aren't too many of us. So that kind of thing, and also the consumer purchaser disclosure project, which is a group of consumer and purchaser organizations have also gotten in agreements with the major health plans like United and Aetna and WellPoint, and they are all part of it; that they would use NQF endorsed measures.

These are primarily the measures I was working on on the clinically enriched project, the idea being when a doc sees a bunch of patients during the day and some of them are from Aetna and some are from United and some are from WellPoint, and you know, the measures are going to be slightly different

depending on which patient you're seeing. That's kind of craziness for the doc. So the idea that they can reach a standard set that they're all going to use, that it just standardizes it and makes it more straightforward for the practitioners out there.

So there are a lot of potential incentives going on for use of NQF members, and then a lot of our own members, people on health systems, and I get calls all the time from Baylor, Henry Ford, you know, some of the big systems saying, "Tell me more about the measure you just endorsed. We're going to put it into play. You know, we're doing it," that kind of thing.

I was going to say we're going to be doing a survey in inventory to see how widespread all of that use is, but it's a whole variety of users out there actually.

DR. LIEBERTHAL: Does NCQA ever use the NQF published measures for their use?

DR. WINKLER: It's the other way around. We tend to endorse the QA measures as NQF endorsed measures, and they tend to, you know, just like the Joint Commission does, you know, they tend to put a flag on it. PCPI does the same thing. This measure is endorsed by NQF and within their sites so they know. That carries, you know, importance for various audiences.

DR. McINERNY: Well, yes. Obviously for CMS currently is the PQRI, Physician Quality Reporting Initiative, where they provide a two percent incentive to organizations that use the outcome measures. There's process measures, tool, I guess for that.

DR. WINKLER: Definitely.

DR. McINERNY: But that NQF has endorsed. But hopefully with CHIPRA, Medicaid will start to do a similar kind of incentive, I expect if I read between the lines for the CHIPRA, and then I think it will be up to

perhaps us to talk to folks who we know to try to get some of the commercial insurers to improve the use of some of these outcome measures in addition to using the HEDIS measures.

DR. WINKLER: Right, yes. So there we are. I think we've talked about the next steps, you know, throughout. We're going to be the intent for measures, call for measures in January. If we need to get back to you, you know, we'll do most of it by E-mail, but something may arise. We may need to do a quick conference call. We'll do it. Who knows?

Once we have a sense of the number of measures, we'll let you know, and the work plan that will go along with it we'll have to figure out. Like I say, it just depends on the amount of measures, and we may need to do some sorting and staging and who knows what it will be?

Donna, did you have a question?

DR. PERSAUD: I don't know if we addressed this, but just one item that I didn't want us to lose track of and whether we should have a representative on the mental health group, or is there a child psychiatrist, at least one on the mental health group, or where can we get some coordination ongoing?

DR. WINKLER: Yes, what's nice is -- Ian, stand up and wave to the folks -- Ian Corbridge is our project manager. Ian happens to be a mental health nurse, and he's going to run the -- do we have a child person on the mental health? I can't remember.

Okay, all right. Yes, okay.

CO-CHAIR HOMER: That wasn't recorded. I don't know if you could step up to the microphone and say that again.

MR. CORBRIDGE: I apologize. We have had the discussion. I guess as far as I know there's not an individual who specifically deals with children psychiatric

issues on the mental health steering committee. So Bonnie and I have had discussion of looking into how can we collaborate to either look to see if we can get someone or if there might be some facilitation or, I guess, working with this steering committee specifically on child health relating to mental health issues.

CO-CHAIR HOMER: So I think maybe to communicate a strong sense to the NQF leadership of this committee that we would like to see child expertise brought onto that other committee.

DR. ZIMA: And I think that's sort of informative. It would be better to have another person, and that I'd be happy to do a little bit of leg work with the president of the American Academy of Child Psychiatry to, you know, let him know that we're interested, and then see if the academy can maybe come with another nomination if the mental health committee feels that they need a child

psychiatrist.

DR. WINKLER: Definitely I hear the message. We need to kind of sort through because I want to say you aren't the only child psychiatrist. I saw a list of names. So I need to kind of, you know -- exactly. Something is triggering very minimally in my brain. I just can't remember the details of it. So we'll definitely talk about it.

And they're meeting next week, and we can check in with them as well, but your point is very well taken and we'll follow up, right?

MR. CORBRIDGE: Thank you. Yes. Thank you.

DR. WINKLER: Okay.

CO-CHAIR HOMER: Any other business, Reva?

DR. WINKLER: I don't think so. I mean, you've all been absolutely wonderful hanging in there with us. This meeting was meant to kind of bring everybody to the same

page of information, what NQF is doing, what this project is all about, getting your feedback on how we should go forward. I think you've done a remarkable job. Your enthusiasm is very much appreciated.

And so please, we do have lunch, but otherwise I don't have anything more on the agenda. So, Charlie, it will be up to you if you--

CO-CHAIR HOMER: I think we stand adjourned, but thank you. You've been terrific.

(Whereupon, at 12:15 p.m., the steering committee meeting was concluded.)