THE NATIONAL QUALITY FORUM

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MEETING OF THE CHILD HEALTH

STEERING COMMITTEE

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Thursday, November 12, 2009

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The Child Health Steering Committee met in the Ambassador Room of the Hilton Washington Embassy Row, located at 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, MEMBER
SHARRON L. DOCHERTY, PhD, CPNP (AC/PC), MEMBER
KATHY J. JENKINS, MD, MPH, MEMBER

ALLAN S. LIEBERTHAL, MD, FAAP, MEMBER
THOMAS McINERNY, MD, MEMBER
MARLENE R. MILLER, MD, MSc, MEMBER
LEE PARTRIDGE, MEMBER
JANE PERKINS, JD, MPH, MEMBER (via telephone)
DONNA PERSAUD, MD, MEMBER
GOUTHAM RAO, MD, MEMBER

ELLEN SCHWALENSTOCKER, PhD, MBA, MEMBER
BONNIE ZIMA, MD, MPH, MEMBER
HELEN BURSTIN, STAFF
IAN CORBRIDGE, STAFF
MELISSA MARINELARENA, STAFF
ASHLEY MORSELL, STAFF
EMMA NOCHOMOVITZ, STAFF

REVA WINKLER, STAFF
BONNIE ZELL, STAFF

NOT PRESENT:

NANCY L. FISHER, MD, MPH, MEMBER

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

PHILLIP KIBORT, MD, MBA, MEMBER

C O N T E N T S

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

9:58 a.m.

CO-CHAIR WEISS: Good morning everybody, if we could begin. Maybe everybody take their seats and let's get started. I'm Marina Weiss and I'm co-chairing with Charlie Homer who has a phone call that he has to do right now, but he'll be with us shortly.

And if you don't mind, I'd like to hold introductions and descriptions of how you, the path by which you got here until Charlie arrives so that he too can hear that. But I think we have some -- I'm not sure exactly what Reva has in mind for us today, but I think she's going to lay out some general perimeters for the meeting. And so let me turn it over to Reva Winkler.

OPERATOR: Ms. Marinelarena?

CO-CHAIR WEISS: Yes.

OPERATOR: Hi, this is the operator handling your call today, are you ready to be transferred into the main

conference?

CO-CHAIR WEISS: Yes, we are.

OPERATOR: Okay. I'm going to transfer you now, you'll hear music for just a moment and when that disappears you can begin.

CO-CHAIR WEISS: Thank you so much.

DR. WINKLER: Hello, is someone on the phone? Anybody there? Okay. Hi everybody, I'm Reva Winkler, I'm one of the NQF staff members, part of the project team that's overseeing this project that you so graciously agreed to part of with us.

What we're going to do in these two days is several things, we want to get you up to speed on what NQF is doing these days, we're a growing organization, some of you are familiar with our work, you've worked with us in the past, some of you less so and we'd like to get everybody sort of in the same place and understanding what NQF does and particularly

what our work in this particular project is.

As well as we have a couple of tasks for this committee to do to help us set the directions and the subsequent activities for this project. And we are focused around outcomes. This is -- this effort is part of a larger project that is funded by the Department of Health and Human Services around patient outcomes.

We actually have it broken up into several pieces, one -- the largest piece of it is focused in on adult outcomes around sort of the top 20 Medicare conditions, if you will, certainly a big focus of the Agency. But in addition to that, we also have -- and they have their own steering committee and technical advisors and all of that.

But in addition to look at some other areas, we also have a steering committee for mental health conditions, primarily Alzheimer's disease, depression and those sort of serious mental illnesses because that's a

slightly different area, so it has its own steering committee and then you all to look at child health.

And so while you're part of a bigger project, you are essentially the decision making body. And we'll talk about the role of the steering committee a little bit more later in the morning, but our focus will be on looking outcomes for child health.

So what I'd like to do, and we'll break whenever Charlie arrives so we can do the introductions, is just kind of start out with sort of an orientation to NQF and some of the things that we think you should be aware of to make it easier for you to be a member of the steering committee and understand what we're asking of you and to play that role.

So this is what we're going to be doing today. The goals of this two day meeting is to do this orientation and we are going to discuss the scope of this project, what do we mean by child health outcomes.

This is going to be one of the, I hope, one of the more interesting discussions that we have this afternoon and tomorrow. And then we'll just talk about NQF standard measure evaluation process rather briefly. Okay, Melissa the next one.

So just I'm sure all of you are aware of what NQF is, but just as a very, very brief summary we are a non-profit organization, we are a membership organization, we have over 400 members now representing a wide variety of stakeholders.

We are specifically a multi-stakeholder organization around issues of quality measurement in health care. Our structure is a typical non-profit structure, but there are a couple of interesting aspects of it.

The Board of Directors oversees all of our work, but our Board of Directors contains representatives from government agencies. We do have a subcommittee of the

board that's very important in the process, that you will be working with, is the consensus standards approval committee.

And then we also are working very closely with the National Priorities Partnership and we'll talk a little bit more about that. And then our leadership network is the chairs and vice chairs of each of our member councils to provide input and advice through those specific stakeholder groups. So, next.

This is a screen shot of NQFs new website, and I would encourage all of you to go there. And you can see that you, over on the right-hand side, you can enroll as a member, anybody can, there's no qualifications besides willingness to fill out the form, to give yourself a log-in a password and access to it.

Because you can create your own dashboard so that when you log in, all the things that are of interest to you within the

very NQF website, will come up and you'll be able to see them without going through all the different screens.

So this particular project is phase III of the outcomes project, child health, so you might want to put that on your dashboard as well as whatever else interests you that we may be doing.

And I encourage you to kind of search through that website because there's just an awful lot of stuff in there. NQF has an awful lot of activities, we're going to touch on a few of them in the next few minutes, but it's fairly wide ranging and you might be interested in some of the other aspects of NQFs activities. And so I encourage you to register and check in with us.

But it will be a way to follow the process that we're going to take measures through for child health. Next one.

Just -- we've given you a copy of

the slides, every organization has a mission and vision statement, this one is ours. And essentially we have a three-pronged mission.

And one is improving the quality by setting our national priorities and goals, and we'll talk more about the National Priorities Partnership as an activity for that.

The second bullet is really the action that we're working on, and that's endorsing national consensus standards for measuring and publically reporting on performance within the health care system. So this is the work we are doing.

And then, we also have activities around promoting the goals through education and outreach programs. So these are the sort of big sort of buckets of activities that NQF pursues and you're working primarily in the second one. Next one.

Again, just to show you our, generally our strategic goals is NQF

essentially endorses -- is the principal body that endorses national health care performance measures, quality indicators or quality of care standards.

So that's -- those are our strategic goals, that's sort of our role in this, the quality enterprise in this landscape. Through measurement we are striving to improve the overall health care system and by the contributions of endorsing measures standardizing measurement on a national basis, we are carrying out our various missions.

NQF is now 10 years old. We celebrated our 10th anniversary this year and I've been around for nine years of it. Though it's a rapidly growing organization, Marina I think you've been around for 10 year of it, from the very beginning. No, she's been there even before me, from even before I think when it was a twinkle in somebody's eye.

NQF has done a lot of work in that

10 years. Over that period, the focus has been on evaluating and endorsing measures as national voluntary consensus standards. There is a growing and continually urgent need for more measures.

It's also an evolutionary process, it's not just essentially more measures as a volume, but better measures as time goes on as everyone embraces measurement and the information we gain from it can be used to drive quality improvement, better measures, more robust measures, different kinds of measures than we initially started out with are needed.

So this is a constantly evolving process, it's not a matter of numbers. So currently at this point there are several drivers that are driving the work we do. Measurement -- measures are needed for accountability programs of various kinds whether they're public reporting, whether they're pay for performance, whether they are,

you know, any other kind of incentivization or accountability program.

Certainly within the measures that we've looked at over the years, there are gaps that need to be filled. Certainly many stakeholders identify, you know, it's great that you've got these measures, but we need measures that do this or provide this kind of information and there are large gaps.

We've been working on filling the gap for measures suitable at the individual physician level, that's essentially the work I've been doing for the last three or four years and we now have a significant number of measures across a large variety of conditions that can be used at the individual level.

Disparity sensitive measures. Issues around disparities are a continual concern and how do you use measurement to help us understand that. There are certainly measurement challenges around how do you -- getting the appropriate data to allow you to

stratify results.

But certainly keeping disparities front and center as an issue and a concern around measurement is definitely one of our priorities. Patient experience in many settings, we do have -- we have endorsed multiple tools for assessing patient experience with care, some for children, some for adults, some for hospitals, some for outpatient.

There are probably areas that still need to be addressed, but it is an important area to get the patient perspective. And then crosscutting areas that aren't so much disease or condition specific, but would apply to all patients either and particularly across settings.

So there are still a lot of areas of -- where measures are needed. And that's going to be one of the issues we're going to ask you to help us deal with, particularly as it pertains to child health outcomes. We need

to figure out how to describe, in a framework, if you will, you know, all the aspects of desirable outcomes.

How do we figure out what we have and what we need? We need some sort of a structure to be able to organize it so that we can either identify existing measures to know that they'll fill one of these slots within our organizational structure or our framework, or if they have not been developed, how do we identify that specific need for measure development.

So these are the primary goals for our project around child health. A couple of key issues as we've reached our 10th year, our portfolio of measures contains about 550 measures and I just completed a project that allowed another 70, so we'll top 600 relatively soon.

And the question is, you know, is it too many, is it too few, but more importantly are they the right measures.

And I think we're seeing, as we're going through our measures maintenance process, that some measures that seem perfectly fine five years ago really don't have a great deal of utility now, they've been superceded by better measures or they're topped out, they aren't being used, they aren't found to be particularly great drivers of quality improvement.

So, this portfolio needs to undergo constant review and modification revision updating. So it is a work, always a work in evolution, it's not a static thing.

Another thing that's changed over the 10 years that NQF has been endorsing measures is data sources, you know, there are some traditional data sources, but there are new data sources. We're getting perhaps closer to having sort of the ultimate data source through electronic health records.

That certainly is not without its challenges, but there seems to be an

accelerated focus on using of -- getting to the point where there are EHRs out there with the capability of supporting performance measurement.

So all of these things overlie all of the work that we do. So we need to keep those in the mack of our minds as considerations as we're looking at how do we measure outcomes for children.

Okay. Again as I mentioned 10 years of experience, we are evolving. We get feedback from all of the various stakeholder members in terms of what their needs are out there for measures. They want to use them, they want information, what do we need.

We need measures that drive us to higher performance. Measures that basically say hey we're doing a good job, you know, 98 percent compliance aren't really very helpful because they're not very actionable. So they're not going to be driving. So there isn't a great deal of enthusiasm for those

kinds of measures.

Shifting towards composite measures, another strong message we're hearing, how do we package information in ways that make it easier for all sorts of stakeholders, but particularly consumers and purchasers to really understand the value of the care that they may be getting or paying for.

Among the composites are concepts around like the perfect care measure, did this -- did a single patient get all five elements of appropriate diabetes care, you know, how many of your patients received all of them.

Way to take measures that are all -- looking very good on performance across the board, but ask the question somewhat differently, raise the bar a little higher and suddenly there's room to improve. So pushing these measures farther is certainly the message we're getting.

I had already mentioned

disparities, so we really want to think about how do we tackle the issues around disparities in the measures that we do.

So when we're looking at the measure specifications, when we're talking with the measure developers, when we know it's a condition that disparities play a role, we need to really dive in and ask how can we use this measure to help us understand more about disparities and potentially drive change around those disparities.

Another huge message we're getting is harmonization and if that's a new term to you, harmonization is the idea of aligning all measures that address a similar issue. For instance, all measures around diabetes.

The definition of who's included, the diabetic by age, by whatever coding you use, shouldn't vary, even just the littlest bit from one measure to the next. Either you're measuring the same group or you're not.

So that harmonization, but we've

come to a place where various measure developers have developed their measures for a wide variety of reasons and potential uses. And so they were working independently and ended up, oh just a little different.

To try and pull these together in a harmonious group, we really need to try and foster alignment along those measures to the degree possible. Certainly, age inclusions are an important one, but some of the definitional issues of who's included in a denominator for any particular condition, who's excluded, those sorts of things; real important aspect of harmonization.

We're hearing from the people who want to use the measures out in the field that without that harmonization, it's just too hard for them to implement a measure that's, you know, this one's this way and the next one's slightly different. So that's going to be a very important overlay to what we're doing.

And we certainly want to see more

measures that promote shared accountability and measurement across episodes of care and certainly across the continuum of care in all settings.

To that end, outcome measures are a critical aspect. That's why you're here. Finally, people are willing to, you know, let's talk outcomes.

For the longest time, process measures have been the focus, the comfort zone, but the need to really start talking about where it counts, what patients care about what, purchasers care about and ultimately all providers and professionals should care about or what ultimately happens to the patient, what are the outcomes. So that's why we're here.

Other issues that we want to try and tackle are appropriateness measures, you know, having a surgery go well and without any complications are great, but did you need it in the first place. Those questions need to

be addressed, still in its infancy, I'm afraid.

Cost and research measures coupled with quality measures, definitely. Big, big interest in that, particularly in the consumer purchaser plan, you know, folks. And I think it's something everyone needs to be aware of and interested in because health care costs are just really quite high.

So those are the kinds of issues around quality measurement that NQF is trying to focus on. We want to keep these in mind as we do the work of this project because we do want -- one of the roles of the staff is to try and keep all of you aware of all the other NQF activities that are ongoing, to keep everything aligned.

We don't really want to function in silos or black boxes, we need to know what's happening in other aspects of the organization.

Just a brief expanse in

disparities. We've had numerous conversations and efforts around disparities and so several conclusions that I want you to be aware of as we go forward looking at potential measures, certainly there are a lot of measures pertaining to child health where disparities are a significant concern.

And so sort of the initials are principles around looking at disparities is that assessment of the potential ways you may characterize patients by race, ethnicity, primary language, SES status should be routine in performance measurement.

And again I think for every -- any measure that we see, we ask the question have you considered it and if not, why not and how can you -- how could you consider it in implementing this measure.

Certainly there are challenges in collecting the data, and so exploring the data collection methods for gathering the information you need to do that.

And then particularly identifying those measures that are particularly disparity sensitive that we know there are issues around disparities and really try and drive to those measures being stratified -- being able to be stratified by these various perimeters such that we can get better information on disparities and monitor and trend and understand performance and changes over time.

Another phrase I mentioned in a previous slide was episodes of care. And rather than looking at real point in time issues where measures are easier to do and have been more common in the past, we want to look at things from a patient perspective and that's an episode.

I mean, it didn't just happen in a single doctor's visit from the patient's perspective, it happened over a period of time and for those with chronic conditions, over a long period of time.

And so one of the efforts that NQF

has been undergoing over the last several years has been looking at some of the more common conditions around episodes of care and creating episode of care frameworks.

And this is an example of a framework around acute MI, it also happens to encompass coronary artery disease when you look at the first bubble. These are our bubble diagrams, I've actually been in the audience at any number of meetings and people have been using our bubble diagrams to sort of demonstrate this concept of an episode of care.

So this is a concept that's growing and finding its way out into the world. And we plan on using this in some of the outcomes work around certain conditions. I'm not sure exactly if we could use it around child health, we'll have to think about it.

But certainly looking at the various phases that a patient experiences under certain conditions, and these help us

identify what the outcomes of interest are. What happens to these patients as they progress through the various phases of their disease or condition and what are going to be the outcomes of interest for that episode of care.

So this is a framework that we're using a lot and at this point it isn't clear to me that it is something we will use in child health, but if you guys can help me figure out a way to do that, I'd like that.

Right now it's not -- I can't quite figure it out, but with all the good minds around the table perhaps we'll be able to. So I wanted to make you aware that this is something, a tool that we are trying to use to the greatest degree possible. Next one. I'm going to take a deep breath. Okay.

I also mentioned the need for a national priorities and goals, certainly as one of NQFs missions. This is a focus on finding the high leverage areas that can drive

the greatest amount of improvement for the effort and the investment made.

We want to align the efforts of all sorts of people. The quality measurement enterprise is a large one, there are lots of organizations working in this space, and if we all work together we're likely to make much more progress than if everybody's doing their own thing.

Certainly individual efforts have been, you know, wonderful and successful but if we can just pull those all together I think we can get some exponential progress and accelerate where we're trying to go.

So about two years ago NQF was involved in working with a group of partners, 32 organizations, very -- you can probably name them, but across the stakeholder landscape organizations that are very much invested in quality measurement and improving health care quality.

They established the National

Priorities Partnership, NQF is one of the partners, but so are a lot of other folks. It is a multi-stakeholder group, it's co-chaired by Don Berwick from IHI and Peggy O'Kane from NCQA.

So this is an activity that NQF is very much involved in, working with the partners to align all of these efforts. Next one.

The work of the National Priorities Partners over the last two years since they launched their activities was to try and identify priority areas and goals to focus on so that with everyone looking towards the same priorities, same goals to build on and have sort of an accelerated additive effort.

Their analysis of various types of measurement, the potential areas and priorities they were able to identify the high impact areas and those are, they came up with six priorities, all right.

For those of you who have been working with the Priorities Partnership, I'm sure these are very familiar to you, for those who are not, it's important -- this is an important work that NQF is doing in trying to align a lot of the work with the partnership.

The first priority area is to -- is around care coordination, cost providers settings and levels of care. The particular current goals are around medication reconciliation, preventable hospital re-admissions and preventable emergency room visits.

So that's -- you'll see in a great many of the work -- a lot of the work that NQF does regardless of the project, these are the kinds of measures that are very important ones and we do flag then as being aligned with the National Priorities Partnership's priorities or one of the goals. You'll also see that in our evaluation form when you do measure evaluation.

The second main goal is in population health, improving preventive services, healthy lifestyle behavior with ultimately -- with an ultimate goal of creating a population or community health index to better understand what's going on, on a bigger picture.

And I'd like to introduce one of our newest colleagues to NQF, Dr. Bonnie Zell, Bonnie wave to the folks. She's leading up our efforts around population health and she'll be talking with you later this afternoon about how do we think about population health and children's health.

How do those two come together, how can we find perhaps meet some of the needs of the population goal or priority at the same time as we're looking at child health outcomes. So we want to keep that in mind.

Another of the priorities is around patient safety. Patient safety, huge, huge issue. We have a lot of activities

within NQF around patient safety. Certainly the goals in this particular NPP area are around mortality, serious adverse events and health care associated infections.

Those are sort of the big ones, but if you're aware of NQFs work in the area of patient, you know that almost from the beginning of its existence, we've had projects around and endorsed the serious reportable events, and it's a growing list.

We've also endorsed the safe practices and they've been revised and updated several times. So these are actually NQFs in-house works and has been sort of the backbones of NQF as a growing organization. So patient safety continues to be a very significant goal in the work that we do. I must have skipped something, there we go.

The fourth one is patient and family engagement. A very important aspect of care delivery, difficult to measure, but nonetheless, very important. So it's a

challenge that the partnership has embraced. How do we do this? Not necessarily quite sure yet, but we've got enough, you know, smart people, good organizations working on it. I think we can probably make some progress in that arena.

Certainly we need more information around informed decision making, more patient experience with care and more around patient self management. So those issues are certainly, and measures around those issues are certainly things that would be very important and very desirable for us if they should come across this project.

The fifth one is end of life care, palliative and end of life care, compassionate care, relief of symptoms, meeting patient needs and access to palliative care and hospice services. Certainly an important aspect of care to be addressed.

And then the last of the priority areas is eliminating ways to -- well ensuring

appropriate care. So it's an appropriateness with some emphasis on overuse. Certainly it's well acknowledge that there is overuse of a lot of different aspects of care. Next one.

And the potential areas that the partnership is looking at, are those that I've listed in appropriate medication use, unnecessary labs, unnecessary diagnostic procedures, unnecessary maternity care, interventions, unnecessary consultations, U.S. Preventive Services Taskforce de-recommendations like don't do it, that are still unfortunately being done, as well as preventable hospitalizations and ED visits and inappropriate end of life care.

So these are areas that the partnership is tackling. And if we see measures that come across this project that support that priority and goal, we will want to note them and consider them within these priorities. Next one.

Just to -- the National Priorities

Partnership is something NQF is active in and we support through our convening function, but it isn't, you know, a wholly owned subsidiary of NQF. So it is sort of a separate entity that we work with very, very closely.

They have their own website I'll point you to, a lot of things going on there, a lot of detail of the goals and priorities that I just briefly summarized is in there, a lot of information.

So feel free, and I encourage you to go check that website out to -- so you have a better understanding of all the stuff going on with the National Priorities Partnership as well as a list of the organizations that are involved.

So we've got priority partnerships, we've got episodes of care, so let's slam it all together and what do we get? This is the bubble diagram plus NPP, courtesy of my boss, Dr. Helen Burstin who we'll introduce ourselves a little more throughly

later.

But this is how we're trying to keep in mind all these different aspects of the work that NQF does. And so these are the kinds of diagrams that help us organize our thinking and organize our work so that we don't lose site of important aspects.

So one of the things that we're going to be asking you to help us think through around child health outcomes is something similar, what are all of the dimensions, what are all of the domains, what are all the aspects of care around -- for child health that we need outcome measures for to both help us identify those outcome measures if they exist, or how do we say we need a measure that looks like this.

So that's going to be really the crux of the project we're asking you to help us with. Further on in terms of NQF activities, we're doing an awful lot of work around IT. Some of the -- led by Dr. Floyd

Eisenberg, we're working with several projects to help the -- accelerate efforts around the EHR development, what health information is needed to support performance measurement.

There has been a lot of money from the recovery and reinvestment act for stimulating use of electronic health records. We need those records to be developed in a way that will become very useful for performance measures.

And so we are certainly involved with all of the variety of efforts both within the federal government and in the private sector too, to come to sort of a common place so that when providers adopt those EHRs they provide the functionality and they can do all the things we hope they'll be able to do because it's not a simple thing.

And go to the next one. Because data is tough. Right now we have a very complex world, a lot of data, a lot of potential data streams, lots of need for data,

lots of need of data analysis.

And so trying to put this into a package that provides the information out is a very difficult one but it's something we've got ongoing activities around.

And some of the more interesting work that we're doing is around the quality data set. This is a set of data elements that we've actually created from the measures that NQF has endorsed to help, you know, how do you break it down into little pieces into data elements so that that data could be captured in electronic platform.

Also looking at how is this embedded in a normal workflow so that measurement isn't -- is part and parcel of care delivery and not something that's done after the fact or as an added burden.

These quality -- the quality data set with these defined data elements in a standardized fashion, the next step is a measure authoring tool so that someone who

wants to create a measure about something, you know, you don't redefine patients with diabetes, there is the definition, go to the QDS, put that up, fine. Now what do you want to measure about them?

There's a good chance we may have already had some of those data elements already defined. Trying to maintain standardization sort of an up-front harmonization, if you will.

So these are some of the ongoing activities that probably won't touch us very directly, but the work we do will impact because the measures we evaluate and move on will get fed into the QDS. Any other comments you want to make about that Helen?

Okay. So I'm okay, where's Charlie? Just because we're running a little ahead of schedule, we're supposed to be introducing ourselves and I sort of hate continuing to talk to you without it. Please use all of your microphones, we are recording

this and there will be a transcript of this meeting. And that transcript will actually be posted on our website, so just keep that in mind.

DR. JENKINS: I have a question. Just in related to what you say, can you give us a little bit more understanding of in this process or perhaps in the general NQF process about the high stakes accountability pay for performance metrics versus what you also alluded to earlier is the more quality improvement perhaps not at that level metrics and just give us the overall on that.

DR. BURSTIN: Of course. So overall, I'm Helen Burstin by the way, we'll do our intros shortly I guess. The overall goal of what NQF does is really to endorse measures that are appropriate for public reporting and quality improvement.

There's expectation for both. The public reporting really is the sort of ultimate goal of many of the NQF endorsed

measures. So there may be measures that are used for internal QI, for example, that wouldn't necessarily rise to the level of being able to pass all the four evaluation criteria that Reva will also go over with you, of an NQF endorsed measure.

So we mainly focus on a higher level, those higher level ones perhaps as you refer to them, and one of the reasons this is especially important is NQF endorsement is required when the federal government chooses to seek to use measures for any of their public reporting programs.

There are options that they can go around it at times, but in general that's been the case. What's a little unique about this situation is that much of that work has been done in the Medicare environment, very little around children and Medicaid, in particular, although health plans have certainly focused on some of this.

So I think because of that, and

certainly Reva knows the work around CHIPRA quite well, there's a lot emerging I think about the way quality measures might get used. I don't know if you want to mention anything about sort of the policy landscape or what's happening with CHIPRA as an important piece of background as we think about the role of these measures.

CO-CHAIR WEISS: Yes. For many of you who follow pediatric issues, I'm sure are well aware that with enactment of the re-authorization Bill that brings the CHIP program. Children's Health Insurance Program forward to the year 2013 that there was added to that Bill a very robust section, I think, that moves both the CHIP program and the Medicaid program so far as it's involved in covering children toward more aggressive posture with respect to the development and use of quality measures.

And so that, the implementation of that section is well underway by the beginning

of 2010 there is supposed to be published a core set of measures that would be used in both programs and some technical advisory work has been going on in that regard and there are things up on the HHS website that you might want to explore into the AHRQ section and such.

So, that is the first wave of measures that are supposed to be out there. And as I say, they are a core set, but there is every expectation on the part of members of Congress who were involved in putting together the quality section of the bill and also the Secretary and folks over at HHS that this is just step one, that there are many other steps to come.

And they involve, as I say, both the development of pediatric measures and also the dissemination and utilization of such measures in the big public programs. So, we are operating in that environment as Helen says. This is an opportune time for NQF to

get involved in this, in a big way. I'm happy to be a part of it.

DR. JENKINS: Just for clarification, do you all use any standard terminology to distinguish like the lower level measures from the higher ones?

Because I know the American College of Cardiology uses performance measures as opposed to quality metrics, just for communication about measures eligible for accountability and pay for performance and public reporting versus things that are not at that standard or there's no standard nomenclature you use?

DR. BURSTIN: We refer to them all as quality measures or performance measures. I think when we specifically refer to them we're thinking about the measures appropriate for consideration for NQF would be those that would be appropriate and could ultimately be used for accountability and public reporting programs. There may be other quality

improvement related measures, but again, we don't call them something else.

DR. JENKINS: Thank you.

DR. BURSTIN: But, you know, it's a really interesting distinction because many people that argue, because we say end quality improvement it's an interesting lens through which to think of it. So for example we just had a very interesting discussion with our consensus standards approval committee about this issue of public reporting and understanding what we mean by quality improvement, for example.

And so as an example we would, for example, think of quality improvement measures that would be reasonable for NQF to consider things that would be reported to providers for feedback and use and benchmarking as opposed to many of the things we typically do in practice kind of back of the envelope, QI, keeping track of things.

Because again, there's a lens

there about reporting and benchmarking even if it is more internal initially.

DR. WINKLER: Just in terms of nomenclature, when measure developers submit measures for consideration by NQF, we actually ask them in its condition whether the measure was developed and intended for the, you know, public reporting as well as QI kind of element and if not, they really shouldn't be submitted if they're truly that lower level QI kind of measure.

And then from a nomenclature perspective, actually once even endorsed by NQF, they're known as voluntary consensus standards.

DR. LIEBERTHAL: Does NQF when they approve or accept a measure require that the measure has been tested in the real world to see if it is both valid and feasible?

DR. WINKLER: Well, that would be highly desirable, but it's been an interesting journey over the last few years. And several

years ago there was a big push to get a lot of measures out into the marketplace and a lot of need by a lot of users, particularly CMS and some of the other big payers.

And so NQF created a category, if you will, for measures that were otherwise met all the criteria with the exception of full field testing. And those measures could be granted a time limited endorsement. That is something that still exists, we're evaluating the utility of that.

It's been around now for about two years, those measures have an automatic review in two years to see and we're finding that a large number, not large, we don't know, but a significant number of them will either need to be abandoned or revised. So we are learning about this process.

Certainly I think it is most desirable that the measures have -- that we have -- it's hard to do a good evaluation if you don't have some information around how

they perform in the field, particularly outcome measures.

So while it's not absolutely required, it certainly is one of the evaluation criteria and I would expect that a measure that hasn't been field tested would be ranked fairly low on that aspect of the criteria.

DR. LIEBERTHAL: Has NQF or anybody set a methodology, a standard methodology for testing of measures?

DR. BURSTIN: NQF has a standard protocol that we require measure developers, who's measures come in as time limited to follow. So they get up to 24 months to submit their testing results.

We, for example, outline number of practices, the kind of reliability, validity testing we would require, that's really just getting to the point where we're starting to get feedback from the first set of measures that went through time limited.

It's clear that some of it's too stringent and some of them can't meet some of those. And the other interesting complexity as Reva mentioned all the work around health IT, is that we're currently at the point where many of our measures are now being, as we're calling them, retooled for use in electronic health records.

And testing in electronic health records is a whole different beast that we don't fully understand.

We've been having some of these discussions, so you might, for example, create, and this is what many of the HR vendors do, an idealized EHR test set that you would run the measure through to indicate how often you're getting the right number of people in the numerator, the right number of people in the denominator, but it doesn't answer issues about implementation in the real world.

Because as we know, that lovely

test set might not relate to some of the implementation challenges we face when EHR is going to practice. So this is definitely a moving target for us, but I think in this particular case, it seems unlikely that many of the outcome measures per se, would be untested.

I mean I think it's easier to make the case a process measure, a simple, you know, translation of a clinical guideline to a if then do something else. It's a little bit easier to imagine than something perhaps that requires adjustment or something like that coming forward and being untested.

DR. WINKLER: But an additional response to Allan's question is we do not have any established method of testing the questions on the evaluation and the submission to the measure developers is open-ended.

Has the measure been tested for reliability? How did you do it? What did you find? As opposed to as yet we haven't set

any, you have to do it this way or you have to do this particular type of testing. So it's an evaluation of the kind of testing that has been done.

DR. RAO: Question over here. How widespread are the measures used by non-CMS payers, what's been the uptake of the measures?

DR. WINKLER: I think it's variable. Certainly we know that there are measures used within health plans, certainly measures used within states. But actually it's a very hard thing for us to get a handle on to really know, because certain areas, organizations within Wisconsin, Minnesota, Massachusetts, some of those states all sorts of efforts around measurement.

So there's just lots happening and most of those usually are using our measures to a greater or lesser degree. But we don't always hear about everything that's going on. I mean I often get calls or e-mails from

hospitals saying, hey we're implementing all of your perinatal measures.

As a more common example, we have a question about, you know, this one. We have no way of really knowing that without those kind of random casual input. So I think it's greater than we even know.

DR. BURSTIN: And actually under our current HHS contract, which this is funded under as well, we're actually doing a formal evaluation assessment to begin to understand what measures have been taken up and actually why. I mean it would be helpful -- it's not just helpful to say who's using what, but why were those picked up and those not and why are some states still using a slight variation.

So this has been an interesting discussion actually, Marina had to just step out for her call, hopefully Charlie will join us soon. We did some work for the work around CHIPRA as they were kind of trying to figure out what those measures would be and I went

through our portfolio and pulled out all the child health measures.

And some of them were very hospital oriented or condition specific, but there's definitely a tension between what the state Medicaid programs for example, think they're -- think they can reasonable accomplish and obviously Lee can talk much more about this, versus perhaps some of the measures that we have.

So I think we're trying to begin to understand that. We're also hoping to build into our process going forward a really vigorous feedback loop so we can find out this measure works well, this measure doesn't really work well.

It may have been specified it worked well in an idealized environment but when it actually hits our hospitals, boy we're picking up lots of unintended patients being put through that particular lens.

DR. PERSAUD: I have two

questions, one does NQF have anything at all to do with process improvement methodology and do people -- do the users respond with these are unfunded mandates?

DR. BURSTIN: NQF has not traditionally been engaged in much of the process improvement work with the exception of our role as part of the National Priorities Partnership.

So what they're doing with those six national goals is they're to focus on six aims which includes quality improvement, payment, accreditation, the whole series of IT, a whole series of various drivers of which measurement, sort of our central focus, is only one sixth, one of the six drivers.

So certainly the NPP is trying to think through those process or improvement steps. And on the other side of this, you know, this is an interesting issue for us, we put forward what we think meets a criteria, as Reva will go over with you, but a fairly

stringent of measures that we think are appropriate to compare apples-to-apples.

That you're really getting a reasonable assessment of somebody's performance, allow end users to make better assessments, usable for people to make better decisions. But we're not the ones who necessarily at the end of the say, pick which measures get used.

So there's only, you know, to date a fairly limited role for us on the actual implementation side. Some of that may be evolving as health reform goes through or doesn't go through over the next couple of months, but it's still an open question for us.

DR. WINKLER: Well that what I was going to do is talk about the overall outcomes project, that this -- it's Charlie. But I think Marina would like to wait until she's back so she can hear your introductions, so we'll still continue on.

Just to set the context, I mentioned that this is part of a large project funded by the Department of Health and Human Services. We do have the three outcomes steering committees. And so we will -- while they have there area focus, there's certainly areas of overlap.

Within the condition specific areas that the main steering committee will look at one of the topics is asthma. Well, asthma certainly has a crossover for child health. So we will be bringing some of those measures both ways.

Right now actually we're not finding a lot of asthma outcome measures, so that's a bit of a struggle. And we can talk about you know, perhaps are we looking under the wrong rocks.

So I don't think it's really critical that a measure has to be in one versus the other. I mean we've got several avenues for some of those measures to be

evaluated and potentially recommended for endorsement. So we'll try to just stay as on top of the potential overlaps as possible.

We are focusing in on crosscutting measures as well as condition specific measures. So it isn't just particular disease states or particular conditions such as surgeries or whatever. So, I mean, we do want to look at things that are appropriate for all children or all patients, whatever is appropriate.

But today, as we've mentioned, we really don't have a lot of child health measures in general and very, very few outcome measures. I think at this point in terms of true outcome measures there's just two or three.

We do have an ongoing project that started earlier in the summer around pediatric cardiac surgery and there will be a group of measures, outcome measures coming forward from that. But again, a very narrow area that

important if that's your, you know, issue, but certainly does not address the vast majority of other issues that are appropriate for children.

And I think that's really the issue. We're going to talk about, a little bit more detail when Marina returns, about those real -- the measures that we have, but you're going to find that they really are very, very narrowly focused such that it only captures a tiny group of the entire child population.

So our goal with this project, to the degree we're able and those measures exist out there, is to expand NQFs current portfolio of child health outcome measures. But the focus is indeed on change order measures, so this project's all about outcomes.

And I think one of the interesting issues will be how do we want to define outcomes. What are outcomes for children? Where do we want to set the boundaries around

measures appropriate for, you know, public reporting, quality improvement within the health care system in terms of child health outcomes.

What are they? What do they look like? What do we -- what would we want in a perfect situation, even if they don't exist today. Go on the next. Okay.

Just to give you an overall view of the bigger project that you're involved in, this is laid out just strictly from a management perspective in phases; phase 1, 2 and 3 and you're in phase 3 just because.

And this is where we've put these two areas that are rather specialized child health and mental health, they have their own steering committees. And so, anything that's labeled patient outcomes phase 3, that's you.

Phases 1 and 2 for just for interest we've sort of lumped all of the top 20 condition into a topic areas that we're looking at. We're looking at respiratory

conditions, particularly asthma and COPD, also some intensive care unit measures, cardiovascular, this is where we've got all the measures, there are 19 candidate outcome measures for cardiovascular, so, you know, big area.

Metabolic, diabetes, chronic kidney disease, not a lot of measures but if you look at our existing portfolio we actually have a large number of outcome measures around diabetes already, not around chronic kidney disease but around diabetes.

Bone and joint, clearly cancer is important, GI/biliary ID and then eye care measures. So those are the topics this whole project and child health has its own special part of it.

That's why you're going to see from the NQF perspective staff wise, there's about -- there are five or six of us that are actually on this project staff doing various aspects of this project, so you may interact

with any of us at any given time.

DR. LIEBERTHAL: Quick question. Asthma was included in the phase 1, and of those, asthma has both pediatric and adult components. I've been on three measures groups for asthma totally dominated by adult providers and allergists. Are we going to be dealing with asthma as a child health issue?

DR. WINKLER: I think we are. I think there's really only one measure that's coming through that we've identified so far. So I think in terms of this framework though for children, if we want to look at specific conditions that are appropriate, and asthma I think certainly would be on that list, we can look and see how best to keep the measures that appropriate for children in your purview.

DR. MCINERNY: Similarly, mental health problems are one of the major areas now that we're dealing with in pediatrics and I'm wondering how are we going to interact with the mental health team, because, you know, how

we treat kids with ADHD and kids with depression and anxiety, et cetera that's critically important and we need some outcome measures for those conditions that are children specific.

DR. WINKLER: I think that at this point we're flexible and open. A lot of it will depend on the input we get from you and from the mental health steering committee, which is meeting next week, as well as what measures get submitted to us for consideration. And if necessary, we can bring the two of you together to talk about common issues if necessary, kind of depends.

At this point, right now there's a lot of unknowns in terms of what measures we're actually going to get in front of to deal with. And so it's great in the theoretical, but when we have the reality of what we're actually going to try and do, if necessary we can do a combined conference call and, you know, learn from each other.

There's absolutely no reason we can't do that. So I think we need to wait to see what actually is going to get put in front of us to understand that, but sharing the work of the various committees where there's overlap I think is an important part because we really do want to foster the alignment, the harmonization, we don't want things going off in different directions without that.

So that's going to be one, I think, the challenges for staff is to help you get there. Well, time for introductions?

CO-CHAIR WEISS: So you have both of us here now and I think all of our other obligations have been discharged, right. So, depending upon how you look upon it, you're either fortunate that we'll be here for the remainder of the meeting or you're stuck with us. But in any event, Charlie Homer, have you introduced yourself?

CO-CHAIR HOMER: I haven't. I know many of you, if not all. My name is

Charlie Homer, pediatrician day job, CEO of the National Initiative for Children's Health Care Quality and I've been privileged to sit on a number of the steering committees here, including the ambulatory steering committee and the hospital outcomes and efficiency steering committee.

DR. WINKLER: Charlie, and to all of you, as you're telling us a bit about yourself and your background in measurement, we also need you to mention if you have any involvement in measure development, any particular interest in these specific measures as a disclosure to the entire committee as well as for the record. So thanks for that.

CO-CHAIR HOMER: So in terms of the record on that, other than those committees, I do chair NCQAs Child Measurement Advisory Panel on the new set of measures that they're developing. Of course, I simply chair that I don't have any other NCQA position.

And NICHQ actually did bring the

BMI measure initially to NQF so I think somebody else may have taken over stewardship of that. But that's our only official measure steward job. We'll later on talk about the other project which NICHQ is doing jointly with NQF. So we'll cover that later.

CO-CHAIR WEISS: So do you want to go in that direction and wind up with me or do you want me to go ahead?

CO-CHAIR HOMER: No, of course.

CO-CHAIR WEISS: All right. Well I'm Marina Weiss and I'm with the March of Dimes and have been for a number of years. And before that worked as an appointee in the Clinton Administration, and before that was on Capitol Hill, and before that was an academic.

So my passion, my greatest area of interest is maternal and child health. I was founding board member of NQF and have rotated off the board some years ago, but continue to be very interested in the quality agenda and quality improvement as well as safety and

such.

And so was instrumental in bringing my own organization into a steering committee that led about 70 organizations here in town and around the country and working together with NACHRI and some others to build a very robust quality section that, as I described earlier, was included in the most recent re-authorization of the Children's Health Insurance Program and extends to Medicaid as well as the CHIP program.

I don't know if any conflicts of interest at all. This is just an area in which the March of Dimes is now deeply involved because of our interest in quality improvement and safety. And so that's it.

MS. MARINELARENA: Hi my name is Melissa Marinelarena and I'm the Project Manager on the child health project. And you'll see my name floating around with the other outcome projects as well. I want to thank you all for coming here and you'll be

hearing a lot from me. So thank you very much.

DR. WINKLER: I'm Reva Winkler. I'm a project consultant to NQF now for the last nine years. I'm an obstetrician gynecologist by training and 20 years of practice experience before coming to NQF nine years ago.

I've been Project Manager for many of the efforts that NQF has done particularly around ambulatory care and consult on a lot of our perinatal work as well. I'm overseeing all of the outcomes work for the entire HHS outcomes contract.

MS. MORSELL Hello, my name's Ashley Morsell. I'm a Research Analyst and I support Reva and Melissa with this project and I was the one sending all the e-mails trying to get everyone here. So I thank everyone for coming and for your cooperation.

DR. MCINERNY: Hi, I'm Tom McInerny from Rochester, New York and I blame

Charlie for getting to this position here. Way back, I forget how many years ago, we did HIPPO, not HIPAA, but HIPPO, H-I-P-P-O, Helping Improve Pediatric Patient Outcomes, an interesting project that Charlie ran through NICHQ with collaboratives and our practice.

I really started as a primary care pediatrician and continued to be a primary care pediatrician, but I moved over to academia about 11 years ago. But our project was a great project on improving how we provided care for children with asthma and we really did I think have some good outcomes from that, we're still using a lot of that.

Then we did another project on ADHD some years later, which I think worked out well. And in my work now as Associate Chair for Clinical Affairs in the Department of Pediatrics working hard to make sure that our inpatient and outpatient care at our children's hospital is doing a lot of quality improvement activities and we're making some

good progress there.

And I now have been on the steering committee for quality improvement for about three years and learning a lot there, working with a lot of good folks. And Allan's going to be joining us, which will be great. He's actually on the committee already, but our first meeting will be next month.

I don't really have any conflicts of interest other than the steering committee on quality improvement. In that sum, there are people like Allan and other people on the steering committee as sort of a subcommittee they're doing some measures development. But I'm personally not involved in that aspect of it.

DR. RAO: Hi I'm Goutham Rao, I'm at the University of Pittsburgh where I run the pediatric obesity center and have done that for about five years. Also teach clinical epidemiology and biostatistics at Pitt Medical School.

This is my first NQF meeting and I think I have to thank Charlie as well for getting me here at some point. I don't have any conflicts of interest.

I had served on an American Board of Medical Specialties Quality Improvement Committee around GERD and hiatal hernia, but they're not very active right now; and a prior committee similar to that from the American Medical Association in about 2002, 2003.

So those are my connections to quality improvement. Looking forward to this meeting very much. Thanks.

DR. JENKINS: Hi everyone. I am Kathy Jenkins. I'm from the Children's Hospital in Boston. I am a cardiologist. I actually have a history of doing measurement development in the field of pediatric cardiology and have developed a number of measures.

In that regard, I am currently the chair of the American College of Cardiology

Quality Metric Workgroup, which is actively involved in doing quality metric development across the breadth of pediatric cardiology practice.

And I do sit on the American College of Cardiology American Heart Association combined performance metric taskforce. I do have one measure related to cardiac surgical mortality that was -- my methodology was partially incorporated into the PDI 6 measure that was put forward and approved by AHRQ I think last year or the year before.

And I am a measurement developer for one of the measures that the Children's Hospital Boston put forward as part of the pediatric cardiac surgical program that was discussed previously, though it's slightly different than the AHRQ methodology.

In addition, I am the Chief -- as Safety and Quality Officer for Children's Hospital Boston and I've been in that position

for the last five and we have done a lot of measurement development for internal benchmarking in that role for internal purposes within the hospital and have been end users to all -- in the pay for performance and Medicaid pay for performance work in Massachusetts, which is a front runner state in this regard.

So I've both been at the front end of measurement development and at the back end of measurement use in all of my various roles.

DR. SCHWALENSTOCKER: Good morning, my name is Ellen Schwalenstocker and I'm acting Vice President of Quality Advocacy and Measurement for the National Association of Children's Hospitals and Related Institutions otherwise known as NACHRI.

NACHRI is a not for profit membership organization similar as Reva was describing NQF, I'm like sort of the words we use to describe NACHRI. About 200, a little over 200 children's hospitals both

freestanding children's hospitals as well as children's hospitals that are parts of larger systems as well as a third group of pediatric specialty hospitals, primarily rehab.

I also am a liaison to the committee from NACHRI that Tom described, the steering committee on quality improvement and management of the American Academy of Pediatrics from NACHRI.

NACHRI has a number of data programs that Case Mix Program, for example, pulls administrative data and therefore serves as a measure provider, if you will, for several of the Joint Commission ORYX measures in terms of potential conflicts of interest.

We also have a system called the Virtual Pediatric Intensive Care System which -- through which in collaboration with a couple of other organizations, including the Child Health Corporation of America, we identified a set of initial pediatric critical care measures that have been endorsed by NQF,

a couple of which would probably fall in the outcomes measure category.

DR. CLARKE: I'm David Clarke from Denver, Colorado and I practiced congenital heart surgery for 30 years and then about five years ago I discontinued clinical practice, but continued with my interest in outcome evaluation.

In the early 2000s after pediatric cardiac surgery finally had a standardized nomenclature between Europe and North America. I was involved in the development of a complexity score which in with the lack of data was developed by consensus of about 50 surgeons, and this is related to cardiac surgery procedures in the Quality Aristotle Complexity Score.

It was in response to the trend that was starting around that same time of evaluating pediatric cardiac surgery based on raw outcome data primarily raw mortality data.

And so basically what was

happening is the largest centers that dealt with the most complex disease were getting a bad rap and were having trouble competing and therefore were reluctant to share their data and was snowballing the wrong way.

And so as a result of this and also in combination with the RAC Score out of Boston, the STS database began to accumulate data along with the European Association for Thoracic Surgery database and the risk adjustment for mortality and the Aristotle Complexity Scores were applied to the analysis for that data so that we finally got at least some risk adjustment into pediatric cardiothoracic surgery.

So at this point in time it's okay. It's not perfect, but it's okay. We're in the process of trying to validate the Aristotle Score based on actual outcomes and we have completed the evaluation of the mortality score using approximately 80,000 patients from the European and the Society of

Thoracical Surgical Database and that should be published any day now in the Journal of Thoracic and Cardiovascular Surgery.

So from that standpoint I guess I do have a conflict, although I have to add that the conflict is definitely not financial. I work on the Aristotle Score and its maintenance on a voluntary basis.

I also have been fairly involved with the STS congenital database. I serve on the database committee and am the Chairman of what's called the data verification subcommittee, which is responsible for performing randomized audits of five centers around the United States that are participants with the STS database every year.

And at this point, we've been doing that for three years and have completed 15 data audits and have found that for the most part the data is very accurate but there are some problems areas in terms of the difficulty collecting certain data fields.

I also do some institutional review board work, so I'm involved in human research on that end as well. And I think that's about it. This is my first meeting for NQF.

DR. PERSAUD: Good morning, I'm Donna Persaud and I guess I would be regarded as one of the end users of all this work that we're going to do and that I am the Chief of Pediatrics for a large safety net organization, it's Parkland Health and Hospital Systems community oriented primary care clinics.

We have 11 clinics, we have 11 school based clinics in addition and we do juvenile justice care as well as homeless outreach and refuge. So we are a large Medicaid practice. We do about 150,000 provider visits a year and about half a million immunizations.

We have just installed EPIC and so I am heavily involved in that development. We

actually developed it -- we did not use EPICs model system, we built it from ground up and I think one of the most interesting things that we did that I shared at the group here is that we separated out the ages very discretely for health maintenance exams.

Whereas people often range those ages, we separated out the 2, 4, 6, 9, 12 and I think that that has given us incisive ability to respond rapidly to changes in what should be done at different ages.

What we're doing right now is trying to extract data from the system to help us understand how we're using it and whether we're promoting outcome. And I think that EPIC was unprepared for the level and our IT staff were unprepared for what we would want to get from the system.

I just came in from Intermountain, from Brent James Quality Training Program, we just did our presentation, it was -- my project was with the correctional facility

actually on decreasing wait times between when inmates complained of toothache to when they got into the dental care for definitive intervention.

And we actually demonstrated results and so I've got a lot in my mind. I think this is exciting and interesting. I have no prior involvement in formal setting of measures, although it is a high interest of my system.

We're looking at both individuals and moving the populations in an urban environment towards health. And we're trying to think beyond just traditional straight primary health care and we think the children, especially with the obesity epidemic, are in such need under other models of care that can move the population towards wellness faster, because we're concerned that getting every child in for primary care visit on schedule might not practically be able to do that.

So thank you for the opportunity.

How did I end up here, someone from Parkland saw the request, the CMO called me, my CV was sent and that was it.

DR. ZIMA: And I'm Bonnie Zima and I think I'm the only child psychiatrist here on the committee. And so I was really interested in your question and I'm very much wondering whether there's a child psychiatrist on the mental health committee as a buddy.

DR. PERSAUD: More than one hopefully.

DR. ZIMA: Is there a child psychiatrist on the mental health committee?

DR. WINKLER: I'll have to double check. I'll get the roster for you.

DR. ZIMA: Okay. And the way I came on this was actually I was on the APAs, the American Psychiatric Association's committee on quality indicators and their Chair saw the announcement and then also Larry Greenhill at Columbia, who is the President of the American Academy of Child Psychiatry also

supported my nomination.

So I think we're clearly in the infancy of developing quality indicators. I have no conflicts of interest. I'm proud to say I've never taken any pharmaceutical industry support for any of my research.

I've been funded predominately by the NIMH as well as the state of California through contracts. I'm not only a child psychiatrist, but a health services researcher and my main role at UCLA is really Associate Director now of the Health Services Research Center.

I'm not Associate Director of the whole department as stated in the materials and I don't think I want to be. And my introduction to quality of care was really an opportunity that was really I think kind of groundbreaking and that was several years ago Dr. Steve Mayberg who is the Director of our state department of mental health had some left over money and to the tune of $1.5

million.

And he turned to the universities of California and said what can you tell me about the quality of care for children in the public mental health system and can you do this in two years.

So it was really amazing because we developed a collaborative infrastructure pretty quickly across five universities within California, developed this strategy, developed 121 quality indicators for the assessment and treatment of ADHD, major depression, conduct disorder, applied it to a statewide sample of children in 22 clinics in 58 counties and used the episodic care methodology.

So what did we find? We actually found very similar to Beth McGlynn's work and as well as Rita Mangione-Smith's work that only about half the kids had any sort of acceptable quality.

We also asked the question did it vary by race, ethnicity, gender, things like

that. The answer was no. If the kid got into care and stayed into care for at least three visits, there was no variation. There was also big issue, and I think this gets back to the whole issue of understudied kids in Medicaid.

In the state of California what happens is that each county can decide whether they're going to use their Medicaid money to fund directly operated clinics or contract out. So one of the big issues on a policy level was where does quality care vary, was it better to have it in a directly operated clinical or contracted out clinic.

And the bottom line was we couldn't pick up any difference. So all of this work then led to an R01 that we have some findings that are going to go under review next month asking the question of quality of care for ADHD in managed care Medicaid program in Los Angeles.

And what's important about that is

I think it's the first study looking at quality and primary care and specialty mental health, okay. And right now we also have an R34 looking at development of a web-based clinician decision support tool to do a better job engaging parents in the process of medication treatment decisions.

It's a very sensitive issue when you're using psychiatric meds and also again, seeing whether we can improve safety and appropriateness in medication. And again this is all focused on Medicaid funded programs. So I think that's it.

MS. PARTRIDGE: I'm Lee Partridge. I'm the Senior Health Policy Advisor with the National Partnership for Women and Families, which is an old consumer advocacy organization, particularly concerned about health care and job working environments, health care benefits, harassment, et cetera.

We started out as the Women's Legal Defense Fund back in the Civil Rights

days to work particularly on that last issue, workplace issue, but over the years we have more into a very, very deeply involved organization around health care quality particularly in respect to women and families and in my case, very definitely woman and families of lower income.

Because I came to the partnership from 25 years in the world of Medicaid and I do remember Dr. Mayberg, you were very fortunate to have him in California. I was the Medicaid director here in the District of Columbia from 1983 to 1992.

We are a medically rich, a very medically rich community with a major children's hospital. The population I served was heavily Hispanic and African American and of course, very interesting differences in the pediatric quality of care for those children, I might say Hispanic and African American.

I then went on and worked with the National Association of State Medicaid

Directors for 10 years and was part of the founding board, as a purchaser as a matter of fact, as an alternate member of the founding board of NQF.

I have been working with NQF now as long as Reva has. I co-chaired the very first nursing home standards committee which was an education for all of us I think. And I have been most recently a member of the perinatal measures committee, which reported measures out last winter.

I don't believe I have any conflict of interest financially. I should share the fact that I too am in the NCQA Child Health Steering Committee and I am currently chairing the Medicare Health Plans Accreditation Committee for NCQA.

And we, of course, looking at both the current standards for health plans that participate in the Medicaid program as well as the clinical measures that are being used in the accreditation of those programs.

DR. DOCHERTY: Hello I'm Sharon Docherty. I'm an Associate Professor at the Duke University School of Nursing where I direct the pediatric acute and chronic care nurse practitioner program. I spend the majority of my time conducting research.

I have several NIH funded studies centering around issues related to the quality of life of infants and children undergoing life sustaining treatments for life threatening illnesses.

Our most recent award is that we have a five year study we're looking at decision making with providers and parents of infants born with life threatening illnesses.

I practice as a pediatric nurse practitioner in the Duke Children's Hospital mainly with chronically ill children and I am here representing the National Association of Pediatric Nurse Practitioners.

And I don't have any conflict of interest. The only thing I can think of is

I'm working on a measure right now to measure technology dependence in some of the children that we're studying. I'm happy to be here.

DR. LIEBERTHAL: I'm Allan Lieberthal. I'm a primary care pediatrician and clinical pediatric pulmonologist at Kaiser Permanente in Panorama City, California, which is in the San Fernando Valley about 10 miles north and one hour during rush hour away from UCLA where Bonnie is.

I'm the new member of the AAP steering committee on quality improvement and management and was nominated by the AAP. I've also been on the measurement interest group subcommittee of that committee for several years.

I was co-chair of the PCPI committee that wrote the acute otitis externa and OME measures and I've been working with Carole Lannon studying the utility of those measures, a study that's nearly complete.

I'm also involved in evidence-

based medicine, I was the co-chair of the original acute otitis media guideline committee for the AAP and now I'm chairing the revision of that guideline committee and I also chaired the AAPs bronchiolitis guideline committee. So I have been involved in quality -- measurement work.

I've also been a member of the NCQA asthma measures committee and those measures are now available for public review. And I'm sitting on a Robert Wood Johnson Foundation panel that's looking at asthma measures and their application for attribution of costs, and that's an ongoing committee. I have no financial conflicts.

DR. BURSTIN: What a great committee. I'm Helen Burstin again, I'm the Senior Vice President for Performance Measures at NQF. I oversee all of our work related to practices, measures, frameworks as the case may be.

I'm coming up on my three-year

anniversary at NQF actually in January. I feel like I still just arrived. Before that I was at AHRQ for seven years where I directed the Center for Primary Care and Prevention in Clinical Partnerships, oversaw the work of U.S. Preventive Services Taskforce.

I'm an internist by training and I still see patients on Friday mornings at a Latino health center here in town.

DR. MCINERNY: Allan reminded me I am an AAP representative to the AMA PCPI and I have attended those meetings fairly regularly. I've been a little disappointed that with just a few, only a few measures that they've really considered have applied to children. Of course they're largely looking at adult measures. So I'm glad that we have this group.

And I wanted to ask a question because I know that the Chair of the Steering Committee on Quality Improvement, Javier Sevilla has sat on the AHRQ CHIPRA committee

that developed through a Delphi process.

They came up with I think 25 measures and I'm trying to figure out how is that going to harmonize with the measures that we're going to be talking about, because they went through quite a bit of work, I think to do that.

CO-CHAIR WEISS: Right. That is the group that I spoke about earlier and the task was to get a set of recommendations together for the Secretary's consideration in meeting the requirements of the Children's Health Insurance Re-authorization section on quality.

That deliberation is currently underway as I understand it, at HHS and they are under obligation, the law calls for them to publish the first core set at the beginning of the month of January of 2010.

But one of -- I also sat on that committee with Javier and one of the things that we did was to tier our recommendations.

And yes there was a set of 25 very specific performance measures that we put on the table, but we also hope we signaled to the community at large that there were other areas that we felt merited further consideration and additional work.

And that is wave 1 or phase 1 of what we hope is a more comprehensive process in looking measures. The emphasis in that core set was on what's out there right now ready to go and where are these measures currently being used at the state level in the Medicaid and CHIP programs and therefore recognizing that that time frame is pretty short, could we get these performance measures up and operational in more venues across the country very quickly.

So that was the emphasis there. So what we do here should feed into the next phases of that larger project.

CO-CHAIR HOMER: Is there anyone on the phone?

MS. PERKINS: I'm Jane Perkins, I'm here.

CO-CHAIR HOMER: Would you like to introduce yourself please?

MS. PERKINS: Sure. I'm the legal director at the National Health Law Program. Most of my work here over the last 25 years has focused on the Medicaid program, in particular EPSDT. I've done writing on this and engaged in policy and litigation on the EPSDT program.

I came to quality measures and I've sort of darted in and out of them over this period of time. But particularly in the late 1990s when I was on a working group that HCFA and the National Academy for State Health Policy sponsored on QZMC ***11:29:47.

Then in the early 2000s I was on a steering committee that was looking at external quality review organizations and their role in improving quality and was sort of the take away from there was just how few

efforts are being aimed at children in the Medicaid programs by the volume of children in the Medicaid program.

We have over the years included and tried to aggressively include performance measures in the litigation that we have won and have, whether it be measure of lead testing or Body Mass Index and have tried to have measures that would apply not only in cases where we've been trying to get preventive and screening part of EPSDT working, but also the treatment part of EPSDT working and with a particular focus on children with special health care needs.

Obviously, as you all know, it can be getting something on the piece of paper is so very difficult and then having all of the different managed care companies using their own computers that measure things differently can be just a screaming headache.

So I was very drawn by your comments earlier as you're giving your

presentation about harmonizing and making these measures ones that will be -- have somehow a maximized value to providers so that they will use them and want to use them. And that's it.

CO-CHAIR HOMER: Thank you Jane.

DR. WINKLER: Anybody else?

MS. PERKINS: I appreciate your having me on the phone by the way. I really appreciate this accommodation.

DR. WINKLER: Thank you Jane. Is there anybody else on the phone? We weren't sure who else might be calling in.

CO-CHAIR HOMER: Did we want members of the audience?

DR. ZELL: I'm Bonnie Zell. I'm Senior Director for Population Health at NQF.

MR. CORBRIDGE: Good morning everyone, my name is Ian Corbridge. I'm, I guess, Project Manager for the mental health project. I'm just sitting on today kind of seeing discussion, it also sounds like there

might kind of be some collaboration that we need to do with this group as well as the mental health group.

So anything that we can do to help facilitate that, that's what we're here for. So thank you very much and have a good day.

CO-CHAIR HOMER: Terrific. Thank you. Well, it looks like we're actually quite -- are we -- well -- Reva, have you not finished?

DR. WINKLER: No.

CO-CHAIR HOMER: Oh, okay I'm sorry. I thought you -- I heard such a wonderful project overview when I was walking in. So let us return to the project overview.

DR. WINKLER: Thank you, now that we all know each other. I asked Melissa to put this slide up. You should all have this in your materials and these are the outcome measures that have been endorsed by NQF.

And this is where I'm going to ask you to start thinking because I think if you

look at this, and there were more than I realized, somebody counted them and said there were 25 of them, but I think if you take a look at them, you'll see that they really don't have a whole lot of rhyme or reason as an organizational group.

They kind of came to us in multiple projects, you know, a couple here and a couple there and a couple here and there and here was what we got. And so at the end of the day, it isn't a very cohesive set of measures.

And one of the things, even though they're all outcome measures, important, address very important issues, one of the things that we really would need your help on is understanding how do we figure out where these fit in and what are the ones we don't have that we truly need.

In other words, sort of the organizational structure, the framework, how are we going to describe child health outcomes

in a way that allows us to plug these in, these measures in to whatever spot they belong in and then say, hmm, here are the empty spots.

And we either need to find existing measures if they exist or, you know, really try and promote the measure development so that we plug the holes so that at the end of the day, rather than having a mish-mash of this, like we do now, we are working towards a coherent organization of outcome measures that meets a variety of needs.

So we need to understand what the dimensions are, we need to understand what those domains should be and, you know, whether it's a two dimensional grid or if it's several two dimensional grids that you slice and dice the issues in a variety of ways, great.

That's really one of the biggest things you can help us with understanding for this project. It will drive both our call for measures and it will drive our analysis on

measures that we need but don't yet have.

So keep in mind as we start talking about things, how might we figure out what that sort of big thing looks like that we can plug the measures into and then figure out where the holes are. So that's kind of what we're working on today. So this should be a reference, and questions at all times.

DR. MCINERNY: I'm going to share my primary care bias. Although certainly measures for children that are hospitalized are important and they often are expensive in terms of their morbidity, mortality and dollars.

We have to keep in mind that a very, very small fraction of children end up in the hospital at any given time or during their lifetime for that matter and that I think most of us would agree that it's the outpatient care for children that's so critically important and how we provide that care for children, the quality of care we

provide for them can dramatically improve outcomes, their health outcomes.

And so my plea would be that, you know, we look and maybe perhaps slice and dice you talk about outpatient outcomes, very important and try and get a significant number of those that we can agree on and, you know, we can do some of the inpatient outcomes, but the numbers are so small that you're not going to affect the vast majority of children with inpatient measures.

DR. WINKLER: I think one of the things that's very clear when you look at the list is the focus is primarily on hospitalized measures and there are measures for hospitalized patients.

And so the fact that there are likely to be others outcomes of interest when you're looking at children as their entire population, again, is what you need you to help us, how do we describe that, how do we portray that, how do we understand so that we

can just say oh we need more patients for, you know, outcome measures for outpatient care.

That's probably a little too vague. We need to be a little bit more -- have a better understanding of what those might look like and the various types of outcomes.

And we've got some ideas to just offer to you as a place to start, but we're hoping this afternoon this will be a discussion that you'll entertain.

And we can do some serious thinking around how do you want to organize this so that we can at the end of the day be able to convey this information to others an get the outcome for the project that we're looking for as well as improved outcomes for kids. Any other questions?

DR. JENKINS: Well just in terms of brainworks, although I think to your point about ambulatory measures, the scope and locus could be very different. We sort of went

through this exercise five years ago for Children's Hospital Boston and ended up choosing the Institute of Medicine STEEEF criteria as our overall framework and I must say having watched it evolve over five years it's worked awfully low.

So I would just offer that up and could show what, you know, how that kind of looked and how a lot of the ornaments hung very nicely under that tree, so.

CO-CHAIR HOMER: I have a technical comment, which is I think the pediatric diagnosis column in here must be pulling from some other peculiar database because it's irrelevant. So in the next version of this just get rid of that field it's random.

MR. CORBRIDGE: I have a comment for that, somehow when we were clearing the fields it seems to be sorting alphabetically instead of by the outcomes or process. So I do apologize for that and we'll try to get it

squared up. Sometimes when you're working with Excel it doesn't always do what you want, so.

MS. PERKINS: This is Jane on the phone, I'm sort of going through the slides looking for the list of them and I'm having trouble coming up with it. Let me just ask a quick question and that is, are all of these measures outcome oriented as opposed to process oriented?

DR. WINKLER: Yes, Jane, I'm sorry. We flipped over to the bundle of materials that was sent to you as the large PDF and it begins on page 10. And yes indeed, this list is all outcome measures intentionally.

There is an additional list of the process measures just for completeness, but it starts out with all of the outcome measures. So you do have that in the large PDF bundle of information that was sent out to you.

MS. PERKINS: And will we -- so is

this group to focus on both or just the outcome?

DR. WINKLER: This is all about outcomes.

MS. PERKINS: Okay.

DR. WINKLER: Okay. So Melissa you can go back to the slides now. Jane we're going to go back to the slides and I'll start with slide number 25.

MS. PERKINS: Okay. Yes.

DR. WINKLER: I'll try and stay as oriented there. So, we did mention that there are some measures around pediatric cardiac surgery, again another hospitalized narrow condition area that are in the pipeline.

So the actual number of outcome measures will change in another couple of months. They are going through the consensus process which we will talk about. Next slide.

But essentially, you know, NQF has experienced the challenges around measuring for child health. The emphasis on most of the

existing measures out there are for adults and particularly older adults.

Certainly the funders of our projects have been those who deal with older adults, we've done a lot of work for CMS and so you kind of get the expected results.

So the children -- measures for children do represent, you know, a relatively small group of all of our endorsed measures, but we do have some issues around measurement for children that we have to sort through.

One is inconsistent definition of children. You know, what's a kid? Age inclusion. Sometimes it's appropriate for the condition, but sometimes it's just an arbitrary, you know, definition and that does make it hard for the set to have any kind of cohesion to it.

Inconsistent application of crosscutting measures. There are a lot of measures that are created that really aren't specific to any particular patient group. But

because they were developed by organizations that only look at adults, things like medication reconciliation, they specify it only for adults.

And so there's no reason it can't be applied to children, but they just don't do it. So these are some of the issues that have made it hard so that there could potentially be more measures appropriate for children, but for whatever reason kids just don't get added to the mix.

So also in terms of outcome measures, overall outcomes is sort of the later measures in development. We're starting to see an upswing in them, but like everything, you know, children, measures for children fall even further behind.

So, you know, these are the struggles and challenges, but I think that we should be able to -- we've already identified, you know, a group of measures, we should certainly be able to hopefully identify a few

more and certainly identify the measures we want to have in fairly specific detail.

Not just we want measures, but what kinds of measures, what should they look like, what should they about so that we could take those to the measure development community and really get some traction on getting those measures developed. So that is a huge goal for this project as well.

So let's just look at the measures we've endorsed for children, and again, most of these are around processes. And you can see that they tend to be some prevention and immunization, but it's mostly the immunization measure.

Some patient experience with care measures, actually there are three or four that are appropriate for children and particularly around adolescents.

Within our perinatal set of measures, some of them very specifically target the neonate or the aspects of pregnancy

such as, you know, elective delivery before 39 weeks, but yes it's perinatal, but the major impact is on the newborn.

We certainly have outpatient measures in certain condition areas. And Marina's already suggested that we need to get the list of the top 20 conditions for children to factor in this. We could probably figure out what they are, but the question is, is it by volume or by cost. You'll tell me and we'll figure that one out.

We've got inpatient measures certainly and we have -- and then the question around safety measures. So, there are many ways of describing outcome measures and again, this is where we need your help what's the best way to do it so that we can describe to a large audience, you know, where we are and where we want to go.

So among the prevention measures you can see them. Charlie takes ownership for the Body Mass Index measure originally. But

you can see they're kind of across the board, a little smattering, you know, a couple for adolescents, a couple for newborns and a little of this and that. I mean they're not very cohesive so we need to think around how do we make this approach cohesive.

I mentioned that the patient experience with care, we do have several versions that are appropriate for kids. So these are endorsed measures so these are nice, we do have this area covered. But if there are other good measures out there that we need to deal with, we certainly don't want to overlook them.

The next one is our perinatal measures. Lee and I both worked on this project and several of the measures are appropriate measures of the newborn neonatal period. But again, this is a hospitalized focused effort, so it does have those limitations.

The next one, where are we on

outpatient measures. You can see we've got some for asthma, one for diabetes, a handful for ADHD, you know, otherwise again, mish-mash, not something that really describes health care for kids. And these are primarily process measures.

So, and then of course we talked about the inpatient measures. Okay. So again it's a bit disjointed, it came to us -- it's the result of years of various activities and here we are.

So we need to deal with the group of measures for kids in a systematic way, if you will. So NQF has several avenues to try and make our portfolio more appropriate for children.

One avenue is retooling measures appropriate for children, you know, some of those measures I mentioned that there's no reason they're -- they have an age cutoff at age 18 or something, you know, get some -- get those reconsidered and expand the age ranges

to whatever is appropriate.

Outcome measures for children, that's why you're here, okay. So among all of NQFs activities around child health, this is an important part of it. More outcome measures for kids and again, at the same time of any of our other efforts, measures applicable to the NPP national priorities and goals that are appropriate to children.

So we have all of these overlapping dovetailing events, but this group is in a position to help us identify existing measures or identify the measures that need to be developed that really can bring all of -- a lot of these together and fill some very important gaps in the portfolio for measurement for children. So, next.

So as I mentioned, these are our project goals. We are going to be calling for measures to be submitted to this project for you to evaluate and consider and potentially recommend for endorsement.

In January, one of the things we're going to specifically ask you to help us with and I'm going to lay it out there now so you can think on it, is where do we target that call for measures to be sure the people who need to hear it, do hear it.

We have our usual avenues, you know, we send it to all of our members and we post it on our website and all this other good stuff, but we know that there are likely to be folks out there who many not get the message that way and you all potentially have contacts you know, that's the world you live in.

Help us be sure that the message and the word gets out so that the measures that exist and are out there get submitted to the project. If we don't have them to work with, we're not going to be very happy with the end result.

So that's sort of assignment number one and we'll, you know, think on it. We will actually formally be asking you to

send us or give us or offer up those suggestions a little bit later.

The other -- so once we have those, it would be nice if we had a group of measures, I don't know, are there six of them out there, are there 60 of them out there? I don't know, perhaps you have a better idea and you can tell us measures that we haven't seen already or that are not already on the list that may be available out there.

So we don't even know how big of an effort, how much work this is going to take actually. So, to the degree that you can help us, those will be useful. Kathy did you want to say something?

DR. JENKINS: I just wanted to offer that we do a regular surveillance of the landscape we call it the state of the universe of pediatric measurement in children that we have somebody updating.

And I would be more than happy to share like the latest and greatest version

which is as best as they could glean and it does incorporate the component of could be adapted for pediatric measures as long as everyone understands that we do have a hospital based focus and don't yell at us if your favorite isn't there.

DR. WINKLER: We are certainly eager to see any of the resources you all might be using in your lives to help pull this together. That's why we use you to really help understand to get out into that world that you all work in so that we can be sure that we're as comprehensive as we can be.

So I mentioned we'll do that call for measures so then your role will be to actually evaluate those measures. NQF has standard measure evaluation criteria and we're going to go through those in some detail so that you understand them and have the opportunity to ask questions about them and about that evaluation process.

But then as I keep mentioning and

I want to emphasize, as an equally important part of this project in terms of the goals, is creating this organizational structure, the framework if you will, to help us understand where the gaps are, identify them such that we can say we need measures, we need measures of functional status for kids with X, whatever, I mean you tell me.

But how do we figure out where those gaps are, how do we describe it, how do we explain this to folks to get the message out there that makes it very straight forward what we're looking for and that it's not ambiguous and it's not so generic that, you know, we don't get what we want in the near term, because that will be very important. Next one.

The keystone of what NQF does is developing consensus. And endorsement of measures is through our formal consensus development process and I just want to go over that briefly because you are overseeing that

process, so I'd like you to be familiar about what it is.

It is a formal process, the consensus that we built pays attention to our overall strategy for measuring and reporting within NQF, multi-stakeholder membership, you've heard that around the table, that's deliberate, intentional and a necessary part of the work that NQF does.

We want -- we include both private and public sector to the group possible, we want to look at the entire continuum of care. Okay, so particularly even though we're narrowed -- narrow ourself to outcomes, it's outcomes from any aspect of care.

So some of our projects are focused in on hospitals or they've been on outpatient. This isn't so much studying specific as it is the outcome measures rather than all measures of the type. So there are many ways we've organized some of our

projects.

Let me just give you this overview of the consensus development process. It is a step wise process, it is our responsibility to shepherd it through the process and meet all of the requirements. This process is -- results in the measures being endorsed to be known as voluntary consensus standards.

This process actually comports to federal law, the 1996 National Technology and Transfer Advancement Act, 1996 as well as OMB Circular 119 which defines voluntary consensus standards.

And what that does is it obligates the federal government to use the measures when they're using measures if we have them available rather than doing their own thing.

And for the most part, over the last 10 years we have enjoyed a very good relationship with our friends in the federal government. They are actually funding this project and the work we're doing and so much

of the work we've done over the last few years.

And they have, to a large degree, held to that and they do use measures endorsed by NQF for all the variety of projects, particularly at CMS. And so the process is, you know, linear over time.

The steering committees role, and we'll go over some of the more details, but you oversee it. You help us make sure that we reach both the project goals as well as follow the consensus development process.

So we constitute the steering committee as a multi-stakeholder group. You are the decision making body, you do represent -- you're the proxy for the NQF membership. Remember the 400 members? Well we can't put them all in a room and have them talk, so we brought you as representatives as a proxy for them.

But we do want the perspectives from all the various stakeholders that's a

critical aspect of the work that NQF does.

So essentially what we'll be doing is reviewing the measures that get submitted to the project according to standard criteria.

You will then be making recommendations, which measures should go forward for endorsement as well as recommendations on things like which measures need to be developed, the framework that we're going to establish to say this is how we want to look in child outcome measures and, you know, we've got these, but we need these.

All of those will be recommendations from this group back to the NQF membership and sort of the world at large, and those are the draft recommendations. We package it up into sort of a standard format report and then it goes out for public comment, a 30-day NQF member and public comment.

We have developed a mechanism where those comments are submitted

electronically and then they get folded into an Excel spreadsheet. We will come back to you, how do we respond to these comments, look at the comments. Sometimes they just reiterate things we've already talked about, that's very common.

But sometimes you will have three, four, five, six organizations sort of with a theme that disagreed with something you did or think you didn't go far enough or whatever.

So, you want to potentially reevaluate some of your recommendations in light of those comments. And we do take the comments very seriously so we'll be coming back to you, we'll have a conference call, we'll pull out the things that we think you really need to pay attention to or you can pull out things you think that need to be, you know, redone.

And so the comment period is really important one because it's a dialog. You're creating a set of recommendations that

at the end of the day is a product of NQF. You're acting as the representatives of the much larger group, so you get their input.

Once we have reconciled the comment period, the review and comment period, we then create a final report, and this is now the draft consensus standards that goes out to the NQF membership for voting, all right, they all get to vote, one of the benefits of membership is voting.

And the results of the voting and any comments that are submitted are taken to the consensus standards approval committee, which is a subcommittee of the board.

The board actually grants endorsements so they have designated a subcommittee to do the focused work around the measure endorsement process. So they look at the work that was done, be sure that we follow the consensus process, really look at the comments, really look at the general information that's come.

Each project has its own character, it has its own set of issues around it so they try and be sure that the process and the end product is really optimal to NQF.

And they make the recommendations to the board and the board ratifies them for the final endorsement as voluntary consensus standards. Then, there's a 30-day appeals period after that.

So all of those steps are important and they are rigorous and they are not flexible to allow us to maintain the integrity of the process. But as I said, you're an integral part of it, we will be keeping you, you know, the biggest amount of work for you guys is up front when we do the draft evaluations and the draft recommendations. What do you want to tell people we should do?

That will be the most -- that will probably be the most intense work, but you will certainly be involved in the review of

the comments that are submitted and then we will keep you up to date on what's happening as we go through the rest of it.

Let's see, when are we due for lunch? Okay, thirty minutes until lunch, can you hang in there. Are they ready at all earlier? Okay. All right. So are there any questions in terms of that? I'm going to go into some of the details, but I wanted to hit the high points so that you know what you got yourself in for. What did you volunteer for really.

DR. RAO: Reva, how do people find out about the public comment period and how is that --

DR. WINKLER: Again, it's another one of those we have the dissemination avenues, it's posted on our website, we do send it, information out to all of our members. Helen are there any other avenues we're using for announcing public comment?

DR. BURSTIN: There's also a

weekly blast that goes out to the public, very wide distribution, it's also on our website. And, you know, at least the last project Reva led on clinically measures we got 800 comments. So that part of that process is --

DR. WINKLER: Yes, from about 100 different --

DR. BURSTIN: -- very robust. Yes.

DR. WINKLER: Yes, it can be. It isn't always, but it can be.

MS. PARTRIDGE: I would also add that the various the eight councils to some degree take some responsibility for reaching out to people that they think might be interested.

When we did the perinatal measures, for example, the National Partnership who collaborated with Childbirth Connection, which is -- their director Maureen Corry was change order-chair of that project and using our combined e-mails and websites

and so on, we tried to reach lots of people we thought wouldn't necessarily know about through the traditional route.

And I'm afraid as a result, we're creating a lot more work for NQF. I think you're going to get a whole bunch of care coordination, Reva.

DR. WINKLER: Public comment is public comment. But again, this would be another role for you all because we will let you know it's now posted for public comment, go here. You can take that e-mail and send it to anybody you want to that you think would be interested.

So you guys are tied into the real child health community and can be a real asset in further dissemination so that we are hearing from the folks out there in terms of how it's playing in Peoria, if you will. So again, these are the kind of roles for you to play as we go through this process. Any other questions?

DR. MCINERNY: Do, for instance, are part of the public the state Medicaid directors and medical directors of major payers, insurers that are particularly interested in child health? Yes?

DR. WINKLER: I guess I'm not sure exactly what your question, when -- you're asking are they involved? Yes, they certainly would be.

For instance, the Association of State Medicaid Directors is one of our members, you know, to the degree that they then distribute it to all 50 or however many state Medicaid directors, Lee can probably speak to it. That was one of the things she, you know, established before she went to the National Partnership I would guess.

MS. PARTRIDGE: Yes, actually the Secretary of Health and Human -- I forget what the departments are called in Michigan, but she's on the NQF board, there's traditionally been a seat for Medicaid on that board. And

there are a variety of ways that internally that the directors communicate with each other.

I think the new group that is really probably increasingly going to be very involved in this is this national, informal National Association of State Medicaid Medical Directors, which is sort of led by Jeff Schiff in Minnesota.

He co-chaired that committee we were talking about, the AHRQ committee and they -- when I was Medicaid director, we tended to have part time medical directors, many of them people who had given up practicing and wanted to kind of keep their hand in, but they really -- most of what they did for me was work on approval of transplants and special procedures and so on.

There's a new breed out there right now increasingly young doctors who make this a career and are career members of their state health departments or state Medicaid

program agencies. And they're very, very active and interesting.

DR. MCINERNY: To sort of follow up, for the major national insurers, I'm not sure how we can ensure we've gotten the attention of the medical directors in those organizations that would have overview of the children's health part of their programs.

Because frankly, my experience is that it's difficult to get their attention, medical directors insurers attention about children's health. They seem to be want to concentrate on adult health, that's who's measures for lots of reasons.

So I just want to try and ensure that somehow we get their attention and then they pay attention and follow through. I don't know Charlie, maybe you can --

CO-CHAIR HOMER: No, I think it's a great point. It's certainly an issue we've wrestled with for a long time. I think to the extent that the national insurers have a

significant Medicaid business, I mean the call I was on earlier was a call with the Medicaid MCO sort of group.

So I think to the extent that Wellpoint, et cetera has a significant book of business in Medicaid, they will be interested in commenting on this, if nothing else for the quote, "burden" end quote, that this will place on their plans.

In fact, the core, certainly looking at the other committees I'm on, the core responders to this do tend to be the large plans or the largest. We tend to get, at least the committees I've been on, that's where you tend to get the most response, or at least a very significant response. So we'll try to get their attention.

CO-CHAIR WEISS: And I think it's also worth pointing out that since it's inception, NQF has made it a point of including the payers both private and public at the table and at all levels of activity

within the organization.

So, the actual ultimate debate and approval process will include input from people who represent at very high levels, the provider, community, the research community, the consumer community, but also the payer community. So there will be efforts made to reach out to them.

DR. WINKLER: One of our eight membership councils is on health plans and it has, I don't even know the number, but it's at least a dozen of the large, and certainly the large ones.

And the reason I know that is I'm just winding up our project on clinically enriched administrative data that is very much something we were focused in on and heard from the regularly.

So, they certainly know about NQF and to the degree we can, you know, put this one in front of them we'll do that.

DR. BURSTIN: Just one other

thought, a lot of the private plans really are very responsive to the large purchasers of health care who are very integrally related to NQF. There's a large coalition between the consumers and the purchaser groups, the consumer purchaser disclosure project who routinely come together to look at these issues.

DR. ZIMA: I had a question. How's the collaboration with NIH going? I think just to follow up with Dr. Lieberthal's question earlier about the validity of the outcomes measures. Is there much discussion there with NIH as far as putting this on the agenda for more federal research money?

CO-CHAIR HOMER: I can answer that in part. I mean I think there are a couple of things. I mean obviously most of this work, as you know, most of the work that NQF kinds of measures we're looking at not only have to be conceptually correct and not only have to be reliable and valid, but then actually have

to be applied in the field.

So that tends to be some distance between NIH and I mean usually running through AHRQ and/or private foundations. So my sense is there's not a direct linear relationship, there may be special areas like the National Children's Study.

And again there was a lot of work to try to convince the National Children's Study to include some child health -- some health services measures in there work and I'm not actually sure where that came up, came out.

So, I mean the other thing that I think is included to some extent in some of our reports, it's when there are gaps, we like to feed that up often to AHRQ which then in theory will feed that up to NIH about gaps in availability of data, knowledge, measures.

So I think it's more a multi-step connection to NIH than a direct broad channel.

DR. WINKLER: But NIH is a member

of NQF and do they still have a seat on the board? Yes, that's what I thought. Just wanted to be sure I wasn't out of date.

So, NIH is definitely a member and active, you know, leader, partner, member within the organization so it's not -- there is a connection for sure.

But I would agree with Charlie for the most part, we tend to be a post-research effort and so a lot of their work may feed into things that ultimately we do, but usually they're a little bit prior to the work that we get into.

CO-CHAIR HOMER: I mean just building on this a little bit, Marina touched on this briefly, one of the things that happened as a result of the advocacy that Marina led in the -- for the CHIPRA legislation was the creation of a new program to develop pediatric measures, broadly.

And that measurement program is about to be launched, actually, we just

yesterday got an announcement from AHRQ, that, you know, watch this space come December they're going to be issuing an RFP for people who are interested.

So again, that's where I see the outcome of this group to the extent that we identified gaps in measures that will require development, which I'm sure we will.

We want to feed into that process so that it's either specified in the next round of our AHRQs language of RFP saying these areas were specifically identified. So I think those are the likely receptor sites for this kind of work.

CO-CHAIR WEISS: Charlie's very kind in saying I led it, I didn't, it was a collaborative effort, but I was certainly deeply engaged and happy to be so. I just really think it's worth paying attention to the fact that a whole purpose of NQF from its very inception has been to drive towards consensus around measures that are in fact

ready for prime time.

And what's really nice about this project and the reason I'm excited about being associated with it is because in being connected to NQF, we have the capacity not only to work our way toward the HHS, AHRQ, and CMS related body of activity, but also to use the consensus process through NQF to come to closure with the provider community, with the research community, with the consumer community and of course with the payers around a set of robust measures.

So the probability that we would be able to launch something here that really is working in the field is actually being used is greater than in any project I've been involved with before. So I'm pretty jazzed about this.

DR. WINKLER: Well I have a few more kind of just points in terms of the roles of the steering committee just that I went over briefly just to be sure I didn't forget

any. So like I say, find out exactly what you volunteered for.

I think for the most part this one I've gone over them and we don't want to minimize any one of these steps, but evaluating the measures will be a relatively intense exercise or activity depending on the number of measures we have and making those recommendations.

We will have an in person meeting of this group again in April and at that meeting is when we will be doing the evaluations and making those recommendation.

Now depending on how many measures we get, like I say if we get six, 60, we may need to have a few preliminary conference calls to kind of get ourselves organized around it. So we're leaving that open-ended until we understand exactly what the amount of work it is we have to organize for.

So be patient with us we'll let you know, that's still a little unclear but I

would anticipate that unless we -- if we've got more than just a handful of measures to deal with, we'll probably need to do some preliminary conference calls to start talking about some of the issues to make you familiar with doing that evaluation process.

CO-CHAIR HOMER: Reva, this will probably come up in the afternoon conversation, but maybe to wet our appetite for it, I mean if you look at the previous work, either the other 12 outcome committees you have other than this one, and all the previous work of NQF, you could slice every single one of them and say for infectious disease.

For example, children get infectious diseases and there are certainly outcome measures that people use in the field of pediatric infectious diseases, pulmonary disease, you know, cystic fibrosis, asthma.

I mean you name it, every -- so depending on how narrowly sliced or what the

criteria are, I mean we could have, you know, a wonderfully rich set of measures which would be great.

But I mean have we thought, I mean because really, this is one of the issues that those of us in child health get sometimes frustrated about where with the adult side you have something on each specific condition and organ and in pediatrics there's one when in fact children have all the same number of organs that adults do and then they also develop.

DR. WINKLER: You know to the degree you can help us figure out how to tackle that, feel free. Again, Charlie's had the experience of being on committees with us where, you know, child health has always been sort of the also on the margin if you will.

How do we bring that in? And we're definitely open to hearing your best ideas of how we can do that. You know, to the degree that the important conditions exist

both in kids as well as with in adults, aligning it because nothing happens big that I know of on their 18th birthday that changes their physiology.

So, you know, I think you bring up a real good point and I think it has a lot to do with measure development out there focus. There's just a lot more focus developing being done by organizations that don't feel they have competency in pediatric issues is the way I've heard it placed.

We don't have pediatricians, so we don't know how to do that. So I think there are some of the limitations we have experienced, so if you want to help try and bring those in, bridge that, help us figure out how to get rid of the dark lines between kids and everyone else and, you know, where should it blend.

That's why -- I think this is a challenging way to think about it and how best is one of the reasons you're here.

CO-CHAIR HOMER: Kathy?

DR. JENKINS: And Charlie just to make the point because I think there's a rich opportunity there, it might be equally important to say which ones are not relevant in kids and make that an explicit line as well.

Because again in my recipient role a lot of the measures, as people have looked for endorsed measures, have simply been applied in kids and especially when you get into the high stakes measurement often there's issues of risk adjustment, small sample sizes, things that are left out of the definition that are being imposed.

So, vetting all of that would be potentially extraordinarily important in both directions.

MS. PARTRIDGE: Kathy mentioned sample size and that might be a way we might find ourselves sorting these down the road. Certain conditions are not going to occur very

often and depending on what you're measuring whether you're looking at a health plan or clinic or a particular practice, it would make no -- they would never implement it because they wouldn't have -- they wouldn't be likely to have the case.

So that doesn't mean we shouldn't endorse it, it just means that you might find that the adoption rate would be pretty limited.

CO-CHAIR HOMER: Good. Yes, Helen.

DR. BURSTIN: Yes, just one more thought. I mean again, a process going forward, we would also be very happy to bring to this committee everything that's going through the other two committees and ask you to look at it through the lens of which of these are actually applicable to kids.

I mean one of things we've discovered at times is we look at a measure and we go, okay, medication reconciliation.

Kids get admitted to hospitals, kids take drugs, but why does that measure start at age 65.

So those are the kind of things, I think, if we bring it to you and we'll try to organize that process if you could give us feedback on which of those would be applicable, that would be really useful. It's as much as we can harmonize it so that it's one measure applicable to both, obviously that would be best of all.

CO-CHAIR WEISS: And going back to a point that Reva mentioned earlier. Apparently when the Department of Health and Human Services asked that this project be initiated, the request was framed in the context of the 20 top conditions for Medicare patients.

And it just occurred to me that maybe we ought to ask for the same bit of information. And I would cut it at least two ways, one is cost and the other one, because

that will be very interesting to the payers of course, and then the other one, of course is frequency.

MS. PARTRIDGE: Yes, I can tell you probably otitis media, respiratory, I mean for common, yes, you'll see -- and of course all the well child. For cost, it's your premises and a few the CPs, spinal bifida, but --

CO-CHAIR WEISS: I don't know that this would be ultimately the way we would go, but I'm sure it would be interesting to know.

MS. PARTRIDGE: No, but I think we -- and it will vary tremendously by state as well, I suspect. There will be some very common and then you'll see there may be for others, there may be certain -- more frequent then you would expect.

I mean I don't, for example, I don't imagine a lot of sickle cell shows up in Idaho.

DR. SCHWALENSTOCKER: Just I

wonder if you could say just a little bit more about the HHS or CMS that overall charge for this program, is that for measures that will be used for say the hospital RK2PU Program ***12:19:38, I love that acronym or PQRI, is there more information you have about the intended use of the measures or kind of the origin of the project?

DR. WINKLER: Helen probably better than that. I mean, I'm not aware of anything that specific just to be used in their programs. And so you can kind of extrapolate, but Helen may have additional information.

DR. BURSTIN: I mean there's clearly been an interest in trying to expand their base of outcomes based measures not surprisingly moving away from some of the more process measures to more outcomes. There's not, as I know any, immediate plans to say, okay, we have these measures let's put them into a program.

But as you know, the measures we put forward can be used in that manner, so nothing clear there other than the fact that there's a strong interest in getting these measures out there in a way that aren't potential for future use.

But again, their initial interest was okay, here's the top 20 Medicare conditions and we said, okay that's a little limiting, could we add children and could we at least add mental health as a starting point.

DR. MCINERNY: I don't know whether people have thought about going back and looking at what the measures that Rita Mangione-Smith developed with Beth McGlynn or the report that she showed that less than half the kids received appropriate care. I'll present -- I do have a little bias there, I actually was involved in the development of those to some extent. I was one of a panel that went to Brand and worked on that awhile,

quite awhile ago.

I think they were, by today's standards, they're probably pretty crude and --

CO-CHAIR HOMER: And I think they're mainly processed aren't they, of whether things were done in offices, that shouldn't have been done.

DR. MCINERNY: Yes, I think you're right, and I don't know how many of them were outcomes, but I just wondered because there may be a few that we could look at and see if make sense and then probably would need to be developed better than they were back then.

CO-CHAIR HOMER: And again one of -- that kind of thing, one of those that informs our thinking about this, but again it's up to the steward or the owner of the measure will then have to decide whether they're willing to submit it and tell us basically all -- they do have to tell us all the specifications as well, which some may not

want to do.

And then they also have to commit to sort of maintaining it at least for a period of time. So there are -- there may be measures -- we may discover that there will be measures out there that people aren't willing to submit.

There may also be measures that look good and have been used, for example, in a research study and are well validated, but have never been applied in sort of a clinical either accountability or improvement process. So that's going to be some of the filtering that will happen once we start going through the process.

MS. PERKINS: This is Jane. In terms of the top 20 conditions that children experience, if there could, I don't know whether this exists, but if there could also be that top 20 list for children who are -- who typically I guess suffer from health disparities, does that kind of thing exist?

I know that for African American populations often things like that do, but --

CO-CHAIR HOMER: I mean we could certainly look at things like MEPS data, National Survey of Child Health Data, certainly those are available to be stratified by race and by in some cases insurance for MEPS so we'd be able to get that kind of data.

DR. SCHWALENSTOCKER: I want to say that every year in ambulatory pediatrics isn't there a report on the top conditions in outpatient and inpatient settings? I can't remember who the authors generally are.

CO-CHAIR HOMER: Yes. That's usually Lisa and Denise Daugherty are usually the authors of that and I mentioned it to Helen.

DR. SCHWALENSTOCKER: Right. But with that, my recollection is that those top conditions vary quite a bit depending on the age subgroup. So in adolescents you're going to see very different top conditions than in

very young children.

CO-CHAIR HOMER: Sure. I mean adolescent the most common reason and the most common costs for adolescents is childbirth, so absolutely clear and second is psychiatric disease and third is trauma.

So I mean it is -- or I might have the trauma and psychiatric disease switched, but I know that childbirth is leading. So, clearly and clearly different at the younger age where, you know, again, childbirth for the baby and then the cost of neonatal care and variety of congenital conditions. So, yes that's a great point.

DR. LIEBERTHAL: For acute conditions, those reports on the top 20 include things like acute otitis media, lower respiratory tract infection and having been involved with the developing guidelines in those areas in looking at those guidelines for potential writing of measures, it's extraordinarily difficult to write process

measures let alone outcome measures.

DR. WINKLER: Anything else because I'm at a logical stopping place and we're lunch.

CO-CHAIR WEISS: Have people take a break and pick up their food and do we want to continue working during lunch or shall we take a little break?

CO-CHAIR HOMER: No, let's say --

CO-CHAIR WEISS: All right, let's take a break then.

MS. PERKINS: Should I call back into this same number then at a set time?

CO-CHAIR HOMER: Yes.

DR. WINKLER: Actually just stay on is preferable.

CO-CHAIR WEISS: Or just stay on.

MS. PERKINS: Okay. I can just stay on.

CO-CHAIR WEISS: Put it on mute and all that.

MS. PERKINS: Yes, okay.

CO-CHAIR HOMER: Very good.

(Whereupon, the foregoing matter went off the record at 12:25 p.m. and went back on the record at 1:17 p.m.)

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

1:17 p.m.

CO-CHAIR HOMER: I hope you had an enjoyable and productive lunch. Looking at the agenda it says Orientation to Project and Role of the Steering Committee, but I think we've done that.

DR. WINKLER: We've done part of it.

CO-CHAIR HOMER: Okay. So would you like to finish that part of it?

DR. WINKLER: Yes, that's the part I wanted to just finish. We had talked about the role of the steering committee and I mentioned that we would be doing measure evaluations by standard criteria. So I just wanted to give you a bit of an overview, we're going to talk in a little more detail about it tomorrow.

But it may help you when we're starting to ask, you know, what kind of measures might be out there realizing we need

-- they would all have to be evaluated against these criteria. So it's important to have a sense of what they are.

And just historically, NQF has always had criteria, they've always had been four major criteria which we'll talk about.

But through the years as things have evolved, I think it was about a year ago, August of 2008 it was a sense that a lot of measures that perhaps weren't as robust as we might like where being endorsed and there was a need to try and raise the bar a little bit.

And so, the criteria was reviewed by the CSAC and revised a bit. And so we're talking about the revisions. And so -- and the whole point of that revision effort was to clarify, strengthen and recommend changes in order to do a couple of things.

We do want to link them to the national priorities. So to the degree that they do have that linkage to the NPP priorities and goals we want to highlight

those and also to higher level performance measures. We really want to raise the bar.

So realize that if you worked with us in the past, in the distant past we are trying to do more. So that perhaps measures that we may have endorsed five years ago would not meet the criteria today.

So greater measure harmonization. We've actually gotten to the point that if the measures aren't harmonized, we won't push them forward for endorsement. It tends to be a great incentive to get the harmonization done with folks. And we've had to be fairly pointed in the need to get harmonization done.

So it isn't, you know, I think there's a lot more work that can be done in that area and it's always a fine line because we are dealing with someone else's intellectual property. But by the same token, the benefits of harmonization are just so obvious that it is a significant priority for us.

Greater emphasis on outcome measures. That's why you're here. And for process measures a tighter outcomes process link, which was real important. You know, what is the evidence that they're -- that this process measure is linked to an important patient outcome.

That will be less of an issue for us because we do have outcome measures, but nonetheless, be aware that those are the questions that stakeholders are asking, you know, why is this important, it's because. Okay, next.

So in terms of the changes, the emphasis, we've always had four criteria of important scientific acceptability, feasibility and usability, but a couple things have changed.

Importance has morphed into important to measure and report. And this is something that people often get very confused in their mind because there are a lot of

really important things out there, but not everything is important to measure and expend energy and resources to measure report and do something with.

So something that may be important doesn't necessarily benefit from an important measure. So -- and this becomes a must pass criteria. And you'll see there are several subcriteria that help define what we mean by important to measure and report.

But it definitely has to do with the balance between the information generated versus the burden it is to collect and crunch the data.

Scientific acceptability, and this is of the measure properties, it isn't so much the evidence that's actually an importance, but it's like that measure, are the specifications precise, do you have adequate definitions, what's the reliability, what's the validity, what's the appropriate risk adjustment, you know, the measure itself, is

it a good, scientifically grounded.

Feasibility, again how easy will this be to implement. What are the issues in implementing, particularly as it comes to data source. And one of the criterias on it if you're not using electronic sources, what's your near term path for, you know, specifying this measure for improved feasibility using health IT.

And then usability, greater emphasis on harmonization, usability is you generate information when you do a measure it's the so what factor.

Who out there is going to be able to use that information to do something with it, make choices, effect change, understand better, whatever, but is it usable in that fashion. So this is how they have morphed over time. Next one.

We also have -- yes.

CO-CHAIR HOMER: May I ask you a question?

DR. WINKLER: Sure Charlie.

CO-CHAIR HOMER: So on some of the other committees I've been on they have a technical panel that answers that number two question of the scientific validity. Do we have that luxury in this?

DR. WINKLER: No, actually given the narrow topic area of child health we will, you know, topic but broad, broad by narrow, we actually don't have any technical advisory panels immediately constituted if there -- depending on the measures we get, and that's why it's a little bit uncertain going forward.

If there were a need to identify some technical advisors that you feel would be necessary to help you, we can do that. But it just, in the work plan in anticipation we don't have that set up. The main steering committee it's looking all the other conditions actually do have several TAPs helping them out.

DR. RAO: Just a question. Do we

have anyone from CMS, for example, that can just tell us well you can't measure that, they don't record that or if they could give us quick advice.

DR. WINKLER: We can always ask that question but realize that CMS is not our only --

DR. RAO: Yes, I know.

DR. WINKLER: Yes.

DR. RAO: It's a possibility.

CO-CHAIR HOMER: So what you're saying is it's not in the plan now, but if we were to get five measures, I mean we happen to have great strength in cardiology here, but for example there is, and you've already had something on that, but for example were we to get 10 measures that were looking at something like that and they all use different severity of illness categories, we might be able to pull in, if we didn't happen to have on this committee --

DR. WINKLER: Right.

CO-CHAIR HOMER: -- the technical expertise that we needed?

DR. WINKLER: Yes. I think that's one of the problems in project planning is really without knowing what measures we have. So I think we have to have -- leave it a little bit open ended to see what we're actually going to be looking at before we know.

But we certainly can bring that additional expertise in if it's your directions. Couple of things just so that you know about the conditions for a measure to be evaluated by NQF and the measure is either in the public domain or we have an intellectual property agreement signed by the measure steward.

The measures have -- are not -- can't be black box measures. We can't hide significant aspects of the measures, they have to be open source, they have to be made available.

You have to be able to see all of the elements, all of the details, you know, all the codes, all the exclusions, all the equations, whatever it is, you need to see it all. And so that's important.

Each measure, there might be a lot of public domain measures out there, but if they don't have an owner that takes responsibility for them that will act as a steward going forward, then we're not able to deal with it because we need a relationship with the measure steward going forward.

Because measures need to periodically be updated, revised, we have questions, someone has to take that responsibility. As we've talked about earlier, the intended use must include both the public reporting, it's the accountability part that is NQFs focus as well as quality improvement.

So the basic, you know, lower level internal QI kind of measures are really

not what NQF is looking for we're looking for the more significant measures.

And then we do ask one of the criteria that we have is that the information be complete. We now use an electronic submission process that helps us manage just a large amount of data and it helps us create the output for you to look at on your evaluation form.

But if half of it's left blank, there's very little for you to work with or any of us to work with. And we're really trying to minimize extraneous attachments and extra documents that we have to, you know, go through.

So to give you a standardized format so you always know where the information about validity and reliability is in your standard evaluation form that we'll give you, we do require that.

So these are just the kind of conditions we put up front on the measure

developer when they're submitting measures to us. So we just wanted you to be aware of it. You know, 10 years ago, you know, a brief description of a measure sent by an e-mail was good enough.

We can't deal with that anymore, things have got to be a lot more detailed and organized and complete in terms of information. So, just the last thing in terms of timeline, where we're going for this whole group.

You're here at the first meeting, we're going to be doing the call for measures right after the first of the year, it's a 30 day call for measures. We want -- we'll need your help to try and be sure we get the word out so that we can keep to that timeline because we actually need all the measures in our hands, you know, just as soon as that closes in 30 days.

Because, like I say, if there are six, you know, we can relax a little bit, if

there are 60, we're going to have some interesting issues with volume.

Our second meeting is -- will be in April, which indeed is the meeting we will ask you to be doing the evaluation and recommendation of those measures. And Melissa will organize asking you all when, you know, what the best date, two days for a meeting in April will be.

And as I said, if indeed we get 60 measures and we have to break them down and do something and do a couple lead in conference calls we'll do that.

We will let you know as soon as we know how many measures there actually will be, but it will be at the end of the 30 day period once the submission closes, we'll check the spreadsheet and count them up and see how many we've got and see how they spread in terms of topic areas and if there's some natural divisions and breakouts.

And then, then we'll take a look

to see if there's additional expertise or whatever that we may need. So we will certainly be back with you once that closes to let you know the work that we have ahead. So is there any questions, kind on -- these are just some real basic how NQF operates issues so that you at least have a general introduction. Kathy?

DR. JENKINS: I just -- what happens next then? Because I have a feeling that a lot of these measures, you know, we're going to have to use what's available now and some of them may be those time limited endorsements and then like how does this go forward and stay together with the national process and AHRQ and others.

DR. WINKLER: The HHS contract that we're working under actually is a four year, potentially four years of work, and we're already working on next year's work plan and the following years work plan and since outcomes is really such a high priority, the

idea that there will be some follow up work depending on what we do, it will lead to the next phase of work that we can anticipate going forward.

So we're likely to have, you know, avenues to if we recommend these measures need to be developed, people get busy and develop them, then, you know, in a year or two we are likely to have another avenue of looking for outcome measures to fill those gaps.

That really is one of the goals from the Agency in terms of doing this work and outcomes is just a huge priority. So this is just sort of a first effort and then the second wave will be another chance to make it better, if you will.

Any other questions? Jane did you have a question or anything, out there in the sky?

MS. PERKINS: No. I'm just sort of, you said 60 so many times I'm starting to freak out every time I hear you say something.

DR. WINKLER: Yes. I don't mean to do that to scare you, I just am trying to be extreme.

DR. CLARKE: I have kind of a comment.

CO-CHAIR HOMER: David had a question, go ahead.

DR. CLARKE: I have kin of a comment and a question. It seems to me that moving forward the framework that we need to end up with has got to be some kind of a hierarchical relationship because other than that, it's going to be very difficult to integrate it into the various databases and so forth so that it can be used easily.

And I don't know that it really matters whether we, you know, start with the hierarchical groups and then, you know, sort of use that framework to recruit measurements or whether we just collect all the measurements and then form the groups later or maybe some combination of both. Can you

comment on that?

DR. WINKLER: What we're going to do this afternoon is we have a couple of things to just put on the table for your consideration and then I'd like you all to discuss it.

And from the things you've already mentioned and the things that you're going to talk about, we're going to actually go out and get some of these things, you want a top 20 list, well we'll go see if we can find them tonight and we'll bring them back to you tomorrow.

And we'll try and do a bit of an organization of your discussion and have a revisit of it tomorrow morning so we can kind of see what did you get, how might we put it together, do a little bit of thinking on the part of the staff tonight, to help see if we can get the beginnings of that organizational structure.

Quite possibly it will be a first

pass and there will be discussion tomorrow morning which then we can give you the second draft by e-mail and we can do one of those sorts of things, so over the next couple of weeks we can kind of build this.

But this is the beginning while we're getting to know each other and we're here, we can have an opportunity to do this kind of collective thinking and see if we can figure out what this picture should look like.

And so however you think it may work best for you, you know, we'll try and do whatever we can to support it, okay?

Okay. I've just got a couple of things, as I mentioned we wanted to offer just a couple of thoughts on outcomes to help you set the scope, and that's essentially what we're doing.

With any project, we have to know what the boundaries, you know, what's in, what's out because otherwise if the entire universe is in, it will drive you crazy. So

we have to know exactly what box are we going to try and live in.

And it's not necessarily a slam dunk decision, so we do want to give you the chance to consider some ways of looking at this.

Just, we are dealing with outcomes, so keep that in mind. And going back to the granddaddy of them all, you know, the definition of an outcome measure and Donabedian's classic construct is referring to changes both desirable and undesirable in individuals and populations that are attributed to health care.

Okay? So that's where we're at. That's kind of what we're talking about. Does anybody have any questions or comments on that as a definition? Ellen?

DR. SCHWALENSTOCKER: So being sort of a Donabedian devotee, I've had this sort of nagging concern today about, and I'm respectful of focusing on outcomes and

recognizing that that's part of our scope, but it seems to me -- or that is our scope, it seems to me that process outcomes link is going to be very important for us.

I think Reva, you mentioned earlier that process outcome link is considered important when considering process measures, but it seems to me we've got to think that way in terms of outcomes measures or how are we going to link them to improving -- link them to specific interventions, if you will, to improve care?

DR. JENKINS: Ellen, do you mean they need to be actionable or you need to know what the actions are that influence the outcomes that can be improved upon is that what you mean or?

DR. SCHWALENSTOCKER: Yes. That's what I mean. Thanks.

DR. WINKLER: I'm sure that will become a discussion point when you look at each of the various measures. But to the

degree that evidence-base -- there is an evidence-base that can answer that question, it is one of the questions in the measure submission.

So that information is there. It's a little bit more tenuous on an outcome measure than it is on a process linking it to an outcome. So we'll have to evaluate each one on its own merits.

DR. MCINERNY: To me the classic example is immunization rates. I mean, that's really a process measure, but you can't wait to see that if you gave a kid a hepatitis B vaccine at birth that they didn't 40 years later get hepatitis B. Most of us won't be around that long.

But, so, you know, can you use the process measure as a proxy because we know that immunizations do greatly reduce disease. So that outcome is -- there is a pretty strong link between that process and the long term outcome. That's always to me a question.

CO-CHAIR HOMER: It always comes up for immunization. I think hospitalization as a quote, "outcome measure" is another one that's, you know, on the fence I would say. And we're just going to have to discuss that.

DR. RAO: Just a comment, in terms of immunizations for example, isn't a process outcome just being offered immunization or offering immunization for the parent rather than actually receiving it just because if they refuse then you still followed the process per se.

DR. WINKLER: I think that there's interest actually in knowing all of those different elements of it, but actually the intervention that is related to outcomes is actually receiving the immunization.

So that is actually the effector, the action item though I think there's a lot of discussion around, you know, patient refusal and that and capturing that data may be of use. But the one that's actually going

to be related outcomes for protecting them against disease is going to be receiving the immunization.

We actually had a specific project focused on harmonization around immunization measures and the immunization guru is very, very strongly felt, you know, it's getting the immunization that's the thing that counts.

DR. LIEBERTHAL: When we talk about process measures and outcome measures we also have to look at who are we measuring. When you're talking about a health care organization, the measuring the outcomes for their population is relatively easy to do and meaningful.

The problem you have when you're evaluating providers is that they do not directly control the outcomes when you're talking about chronic disease. For example, in asthma a patient may see multiple providers plus socioeconomic adherence many, many other things contribute to the outcomes that are

unrelated to what the provider did.

And it becomes a real difficult problem when you try to attribute outcomes to individual providers.

DR. WINKLER: In this particular case we are not designating the level of analysis for outcome measures per se and many of these measures, for a lot of technical reasons, but for a lot of philosophical reasons may only be applicable at larger levels of analysis such as at a hospital level, at a plan level, at a large group level.

One is just sheer numbers, but I think each measure would have to be evaluated on a -- as an individual at one, the measure developer is going to designate what levels of analysis they believe it's suitable for and then that will be part of your evaluation as to what levels of analysis you believe that to be that they presented the case for or not.

So it's conceivable that among the

list of outcome measures that you recommend, some will be at certain levels and some -- and none of them may be at individual provider levels, but may be at larger levels of aggregation and analysis, and that's perfectly fine.

CO-CHAIR HOMER: The only restriction that we're proposing here is the one Donabedian talks about, that is that we can reasonably attribute these to health care.

DR. WINKLER: Yes.

MS. PERKINS: I actually -- I have a question about that.

CO-CHAIR HOMER: Yes, it's a good -- go ahead.

MS. PERKINS: Yes, what does it mean? Does it include education, does it include things like personal care services that children with chronic needs really do use and need?

CO-CHAIR HOMER: Well for example, so I think on the table for discussion, so

maybe by the end of the day we'll have an answer to it, when we were just talking about this as Chairs across my e-mail list was a report from some California foundation talking about the, you know, impact on academic achievement of child health.

So in that context it's probably fair for us to at least at a first pass say to put on the table whether we want an index of academic achievement as a potential outcome measure.

I'm not saying on or not, but I mean I think that's a potential outcome measure that we should at least think about is that in or out of scope and then I think we as a group probably would want to wrestle with, well what proportion of variance, for example, in a population outcome measures could be achieving at the health care and would we be willing to hold any health care organization accountable for that outcome.

And if we would say yes, then, you

know, we probably should at least be within our scope. So that would be my guess. But as opposed to, well again we're not really looking at processes.

I mean if we -- I don't think we should be looking at processes within schools or, you know, whether there's a school lunch program or not even though that may have a health outcome that we care about, you know, we're looking at outcomes.

But I think to me the critical question is can the outcome or are we or would somebody be willing to hold a health care delivery organization at some level between provider and Kaiser, you know, probably at that range accountable for an outcome.

DR. PERSAUD: Well I think what that raises is really that one outcome isn't depending on just one thing, it's a matter of attributable cost.

CO-CHAIR HOMER: Right.

DR. PERSAUD: And so the reason

that immunizations are almost a proxy for lower infection rates is because they are such a large proportion regression contributor to the outcome.

For me in prevention medicine, I think we should start to entertain those discussions about academic achievement because I think there is a theoretical relationship between the health care provider than academic achievement.

It's just that the contribution is varied and maybe even variable across systems and maybe those are the kinds of things that we should start to address.

CO-CHAIR HOMER: And again, as the materials, we said when we start looking at outcome measures there's an assumption that we will need to include, risk adjustment for different categories of risk and/or stratification which is the approach that NQF uses for dealing with socioeconomic and racial disparities rather than risk adjustment.

So that's -- that, for example, race or a class is a stronger determinant of outcome or a major determinant of some of these broad outcomes is kind of accepted and is a given and not a reason that we shouldn't include an outcome that has those as major determinants.

We would just need to see when we see a measure come in, the measure proposer would have to tell us how the measure either adjusts for that or proposes to collect data and stratify that depending on what the risk characteristic is.

I'm sorry, there are a couple -- the ones that were in order, I know Ellen has had her hand up for awhile. Who else has -- I prefer to keep a queue here. So it was Ellen, Kathy, Lee. Okay, great.

DR. SCHWALENSTOCKER: So just a scope question, again, sometimes we call things like experience with care intermediate outcomes, are we considering them or is that

an open question, should we consider them in the scope of outcomes measures?

DR. WINKLER: It's more your second question, should we.

CO-CHAIR HOMER: Okay. Kathy?

DR. JENKINS: Charlie when you just said that there had to be attributions to a health care organization or entity I guess I got a little confused because I thought that there could be both public health perspective, population based health outcomes that for example the state of Massachusetts could fill ownership of or an accountable role to play that could potentially be something within the boundaries of your question before about attribution that we could consider. Is that not correct?

CO-CHAIR HOMER: So as that evolved, I've been on different committees and the sense in the past I've been on was if it was that the health care system, health care delivery system had to have a potential impact

on that.

DR. JENKINS: Well in some ways you could say that a state is a provider of health care in a variety of ways, certainly as a payer, as an insurer through their Medicare programs.

So, you know, I don't think it's too big of a stretch and in fact one of the things Bonnie is going to propose is how do we, you know, look at these two together from the more traditional way that NQF has always looked at, you know, specific levels of analysis versus, you know, we do care about the population and the contributions to the larger -- how do we make that jump?

Where are they connected? What are those connections? And this, particularly around children seems to be a good project to explore some of that to figure out how we might begin to think that through. And so that's why Bonnie's going to talk a little bit about some of these things together.

I think a lot of these are a little bit open and you're input is helping us try and figure out maybe the best way to go forward. So it's not as if there's some absolutes here, but I think Charlie's right.

I don't think we want to range so far out there that we're worrying about what's going on in the schools too much, you know, and hold the school accountable as opposed to need to be something that's a little more health care oriented to keep it at least within a reasonable kind of purview for us to deal with.

CO-CHAIR HOMER: Lee?

MS. PARTRIDGE: Charlie you're raising the schools of course is a very significant departure from what we normally do around an NQF steering committee table. And I was thinking, we do talk about missed school days, which is often tied, particularly to control of certain chronic conditions.

And that tie could be quite tight

I think. If we end up going in that direction, I think then the call for measures, Reva, really has to say to people this is not a traditional call for measures.

DR. WINKLER: Let me do something, go ahead two slides. This is a list of the types of outcome measures that actually we've used in the HHS proposal, but I also put to the main steering committee who are doing, you know, all the 20 conditions things and asked them.

You know, because I've heard people say oh that's not really an outcome measure, maybe it is maybe it's not. So the question I would pose to you is, do you think these are -- should be included within your scope of what are outcome measures.

And you'll see, whoever asked the question about patient experience with care, it's up there. But let's just take them one by one and be sure that you would include these, because this actually is setting the

framework for what the main steering committee is going to use.

They actually want to see these type of measures against their 20 conditions, that's their framework, okay. And it may not be what you want to use, but it's certainly one way to go.

One is patient function or symptoms or sort of the health related quality of life. When you talk about function, to me a measure of function might be missed days of work, missed days of school, able to do your usual activities, whatever.

So measures of function is it an outcome measure or not?

CO-CHAIR HOMER: Sure.

DR. WINKLER: Yes. Okay. Nobody disagreed. Then we have intermediate clinical outcomes and we've got several measures like this, you know, blood pressure control of, you know, less than 130 over 80 kind of thing. Good intermediate outcome.

The third one is patient experience with care or some assessment of patient knowledge of understanding of their health condition, health risk status, motivation, kind of those patient thinking kinds of things. Outcome measures?

CO-CHAIR HOMER: I would have a split vote on that to tell you the truth.

DR. WINKLER: You'd have split vote?

CO-CHAIR HOMER: Yes, I think you could --

DR. WINKLER: What do you want to split?

CO-CHAIR HOMER: I would say experience of care is an outcome measure, it's one of the core dimensions of quality and knowledge per se, is not in my view an outcome because knowledge is not really -- knowledge is a beautiful thing, but it doesn't relate to either health related behaviors or health outcomes. So I personally would exclude

knowledge.

But that's -- so that's why I said I might be a splitter on that and not consider them all part of the same.

DR. LIEBERTHAL: Patient, I don't know, knowledge and understanding and their adherence is a function of a system that provides the education in a way that the patient can absorb it and understand it, which is not our normal way of interacting with patients.

And I think that this is a key outcome when looking at overall health because if the patient, if we have not conveyed the knowledge at the level that the patient can understand it and effect their behavior and I'm not quite sure the best way to do that, the outcomes may be disconnected from the health care provided.

DR. CLARKE: Well, it seems to me that the outcome, I agree patient experience with care which is patient satisfaction is an

outcome. But the outcome is the behavior and the adherence to care and the acceptance of the prescribed care and the actual follow through, that's the outcome.

I don't think you can measure accurate the knowledge, understanding, motivation and all that stuff.

DR. MCINERNY: Well I think now that we have motivational intervention available, we probably could significantly improve outcomes for things like smoking cessation and prevention or treatment of obesity; however, I don't know if that link has been thoroughly studied.

But it seems to me that the good old loose weight because I told you to or stop smoking because I told you to clearly doesn't work. And on the other hand if one uses motivational intervention that -- I've seen some indication that that probably is far more likely to improve outcomes in the long run. But that's going to be asking a lot of the

system.

DR. PERSAUD: I think that bullet three is probably a continuum of processes that lead up to an outcome and we've got too many things probably lumped together.

I would throw in that probably the big buzz word in all motivation now is readiness for change in case you want to add anything in there that's going to give you an idea of where the person is moving between understanding to doing something, I think readiness for change is in there.

So I would propose that maybe three just be separated out or we need to just understand. I think three is a continuum that some of those are process, some of those are intermediate and some are outcome.

DR. RAO: Yes, I think one of the concerns that I think Charlie raised as well as I think you can have absolutely no knowledge of something and can still follow the behavior and have a positive outcome. And

of course you can be very knowledgeable and do absolutely nothing.

The other problem is measuring those knowledge outcomes would be extremely difficult I think from a systems standpoint too.

DR. ZIMA: I do agree we have to unbundle this. And one resource is Barbara Rimer I-M-E-R, she has a textbook on health behavior and health provider education. And what she taught me through that book, and it's in the fourth edition now, is that there's three decades of work on social sciences.

And to me things like knowledge, attitudes, norms, it's already been elegantly written. And what IOM is really encouraging us to do is to integrate these behavioral theories in our interventions. So I think it maybe needs its own box as far as potential mediators of quality.

CO-CHAIR HOMER: So what I heard in that discussion was I think general

recognition that experience is an outcome and some sense that the rest of them are on a continuum towards leading to outcomes and which of those we actually include.

A, we need a better categorization of them and this is a little less sophisticated than it should be. And I think once we have that, I think we would need to revisit further whether we consider -- the sense I had was most people think these are important steps on the way to behavior change.

Whether they should be measured, all measured and considered as quote, "outcomes" I think we have not yet come to consensus on. That's what I -- did I capture that?

DR. WINKLER: Okay. We can try and redraft it based on your input. Because I think some -- because I'm thinking of this as being sort of the backbone of this call for measures, you know, we are looking for measures of these types and describe them.

So the degree we can make them as clear and understandable to a broad audience is important. So we'll kind of redraft them and get them back to you for further thinking.

The next one is service utilization as a proxy for outcome and under this comes readmissions --

CO-CHAIR HOMER: Or admissions- --

DR. WINKLER: -- or admissions for things that perhaps didn't need to happen or ER visits or, you know, those sorts of things. That's what's meant there. Any question about those being outcomes?

DR. LIEBERTHAL: Yes, when you use the term service utilization and then relate that to an example is readmissions, I'm not quite sure I understand the wording or how service utilization --

CO-CHAIR HOMER: for example it would be --

DR. LIEBERTHAL: Yes, I'm not -- the terminology doesn't --

DR. WINKLER: Work for you?
DR. LIEBERTHAL: -- work for me. I wouldn't have come to readmissions after reading that statement.
DR. WINKLER: Okay.
CO-CHAIR HOMER: So it's not question --
DR. LIEBERTHAL: It's not clear.
CO-CHAIR HOMER: -- with the content, it's more the words that are described --
DR. LIEBERTHAL: The clear, it isn't clear to somebody who hasn't seen it before.
CO-CHAIR HOMER: But the concept though, for example, the potentially preventable hospitalization for asthma of something like that would be a kosher -- you consider that an outcome measure?
DR. LIEBERTHAL: Yes.
CO-CHAIR HOMER: Okay. Bonnie.
DR. ZIMA: There seems to be a lot

of emphasis on avoiding of excessive services, but how about dropout? How are you handling that?

CO-CHAIR HOMER: So meaning either under use --

DR. ZIMA: Yes.

CO-CHAIR HOMER: -- people who are not receiving therapy that they should be receiving?

DR. ZIMA: Yes. It's certainly a big issue in mental health. I mean the average number of visits for a child in a community mental health center is one.

DR. WINKLER: These tend to be, you know, the more efficacy kind of measures in terms of in process it's how many of them are doing whatever needs to be done. The related outcome though would be what we'd be looking for.

So even if patients drop out, presumably their outcome will suffer as well. So that would be captured in the actual

outcome measure for this particular approach. You know, that's the difference between process and outcome measures I think.

CO-CHAIR HOMER: I think that's right. So I guess the question, if you had no other data but simply data that said 46 percent of children didn't complete their course of children in one program compared to 10 percent in some, you know, would that be sufficient information on outcome to allow you to make a decision that the outcomes are better in one or the other assuming the treatment is efficacious?

DR. ZIMA: It's interesting because there is a body of literature that shows that mental health care is ineffective in real world treatment settings.

CO-CHAIR HOMER: Ineffective?

DR. ZIMA: Ineffective using either weightless control or children who have dropped out of care.

CO-CHAIR HOMER: So that would say

that -- so that would answer your question which is that we couldn't use --

DR. ZIMA: I don't know.

CO-CHAIR HOMER: -- outcome --

DR. ZIMA: It's a murky issue, but I think dropout is a big problem with our child mental health.

CO-CHAIR HOMER: So again, one of my general principles on sort of quality measures, again, this is more my philosophy maybe not my Chair role, but maybe it is.

I mean, a quality measure particularly if we're either asking -- we're either holding somebody accountable, which means basically you'll get paid more or less or you'll get a contract or not less ***1:58:57 or you're going to do a quality improvement program which is we would like you to achieve a higher level of performance.

You have to have a fair degree of confidence that what you're articulating is quote, "The right thing to so," I mean the

right thing for the right patient at the right time.

So if it's a murky area, which will come up I think at our conversations repeatedly over the next several months, probably means not ready for prime time. I mean not ready for us to endorse as a measure that NQF is going to stand behind and say plans or practices or hospitals or providers can and should measure this element.

It's a very different framework from a research framework. Kathy?

DR. JENKINS: I had the same comment as Allan about the wording, but what I read into it was the question about whether costs of care could be considered an outcome measure and I guess my answer is yes particularly through the lense of efficiency.

And if that's not what was meant by the fourth bullet then I think it should be up there somewhere.

DR. WINKLER: Yes, cost of care is

an outcome measure. I can tell you that just in the weirdness and the way these projects are set up, they actually is the different projects looking at the cost of care elements of it.

So I think we'll put it there, but it won't be what we call for just because by contract it's out of scope not by conceptualization it's out. But I don't -- I think putting it there to include it so we know that we're not deliberately excluding it from our thinking is appropriate. So thank you Kathy.

Any other comments or questions, we move down the list. Okay. The next one is non-morality morbidity related to disease control and treatment.

And sort of classic one is, you know, amputation as a result of poor diabetic control, you know, serious preventable morbidity or dialysis or something like that that on the long term. So I think there are

some other ones.

And then the next one is health care required adverse event or complication. These are the not so desirable outcomes and then of course mortality.

So the question I'll ask you with the wordsmithing and the caveats we've already talked about, this to me seems like it forms -- is going to form the basis for our call for measures that we're looking for measures of all of these types.

I think we'll need more, but is there any -- can you, off the top of your head at this point, think of anything else that's not there? And we're going to have further discussion, but --

CO-CHAIR HOMER: Development. So I mean to some extent you could put it under your patient function, symptoms, health related quality but again that's sort of --

DR. WINKLER: You're talking about physical development, right?

CO-CHAIR HOMER: I'm talking about physical, cognitive --

DR. WINKLER: Cognitive, the whole thing, right.

CO-CHAIR HOMER: -- emotional development. I'm talking about all the dimensions because that's, I mean that's the critical outcome for childhood that's not captured well.

DR. WINKLER: Does everybody agree that that's particularly especially for children?

DR. DOCHERTY: I saw that under that patient function, health related quality of life, physical, mental, social, I was looking for that and that's where --

DR. WINKLER: Okay.

CO-CHAIR HOMER: Yes, I think that is where it would --

DR. DOCHERTY: -- needs to be more specified.

CO-CHAIR HOMER: -- fit. I think

for us, I think we should specify that in order to get it.

DR. WINKLER: Okay. Works for me.

CO-CHAIR WEISS: I like it. If we're finished with that I want to go to that same bullet but with a slightly different item.

DR. MCINERNY: Just a comment on what Charlie said, I think, you know, the idea of getting children into early intervention if we do a good screening job for developmental delays is at a -- being in early intervention, is that an outcome, no probably not.

But is it a good proxy for an outcome or do we have to follow them through their early intervention and see if somehow they were ready for kindergarten because of the early intervention because you identified as developmentally delayed too. I have a problem with knowing exactly how you -- where you go with that.

CO-CHAIR HOMER: Without answering

the question, I think what we'll have to wrestle with is the certainty of the link.

I mean really that's a process outcome connection that is being in an early intervention program, process that leads to an outcome and it depends on how confident we are that that process -- I mean if it was as clear as immunization linked to the other ones, then it would be fine.

If it weren't, then it's a process measure and maybe a very legitimate process measure that we would want -- that a committee that would be looking at, you know, child development process measures would look at. The only caveat I have is whether that counts as service utilization as a proxy for an outcome.

DR. ZIMA: It's an interesting point because I think that we know that detection doesn't necessarily improve access to care. So as we kind of go down this slow, I mean how much would a recommendation of

detection be linked then to recommendation related to service use than to outcome.

CO-CHAIR HOMER: I'd be absolutely confident in saying for example, doing a developmental screen is a process measure and not an outcome measure. And even filling out a referral form, the EPS, you know, early intervention program is a process measure and not an outcome measure.

Whether somebody's enrolled in an early intervention program versus whether they are ready for school at age five, which would be a better outcome measure I think is really for us to wrestle with.

DR. RAO: Just thinking about a possible, you know, outcome measure that might cross a lot of different boundaries and categories, what about physical fitness if somebody -- I would propose that as an outcome, where would that fit in? Is it a functional sort of thing, is it really related to health care or --

DR. DOCHERTY: That seems to me if we're going to add a bullet on growth and development it seems to fit under that.

DR. RAO: Yes, as a separate thing under growth and development.

DR. DOCHERTY: Yes. Well as part of the growth and development would be physical functioning, you know, appropriate levels physical functioning at the age. And I wasn't understanding were people questioning whether or not growth and development could be an outcome at all?

Because we certainly use that a lot with the chronically ill children. If they've been in the hospital we look at, you know, what kinds of growth and development outcomes are we seeing when they're -- so we use that a lot for the chronically ill.

DR. CLARKE: I had a comment about morbidity first and then about mortality. Actually bullets five and six I think are the same thing, they're both clinical morbidity.

And what we found when we tried to objectively evaluate morbidity in the large group of cardiac surgery patients that we looked at was that for most adverse events that are temporary and reversible length of stay in the hospital serves as a fairly good surrogate for measuring that.

However, the occasional durable adverse event like a neurological injury or heart block or, you know, a few other sort of like permanent dialysis those kinds of things, are very, very difficult to measure because you find that unless you weight them just incredibly heavy, they contribute nothing because they're so infrequent.

And so just some words about measuring morbidity and how difficult it is and how we may, you know, I think it's important, but you may have to accept something that less than perfect in order to make it usable.

And then as far as mortality and

also morbidity together, I think that in the pediatric arena, this is where some sort of risk or complexity adjustment is vital. Because if were going to make these public, it's key by the door ***2:07:45.

CO-CHAIR HOMER: Well agreed. And just on my comment earlier, just echoing the NQF standards, the NQF acknowledges that outcome measures need to be risk adjusted unless proven otherwise. So, Kathy?

DR. JENKINS: The other thing I don't see there is I see patient functioning, but I don't see patient and family functioning which in a pediatric context I think probably does deserve to be an outcome measure, whether it's parent satisfaction, family functioning, what -- across the board to kind of -- maybe that's about scope, but I think it needs to be there.

CO-CHAIR WEISS: Well we probably need to say that about a number of these items, especially for the smaller children.

We're really talking about parental satisfaction rather than talking about toddler satisfaction, for example.

I wanted to go to bullet number one under the patient function and just say from the perspective from those of us who are in the world of advocacy and trying to see to it that things are reimbursable and whatnot through various programs be they private or public, one of the things that we run into a lot is the issue of function.

And the standard that we run up against is that a function is not improving then it cannot be reimbursed. But for children especially it seems to be necessary to stipulate that maintenance of function is important. So I would like to see that there in some way.

MS. PERKINS: Also under Medicaid you don't have to be improving to be reimbursed for children.

DR. JENKINS: Jane, could you

speak up?

MS. PERKINS: I just said also under Medicaid you don't have to be improving to be -- for there to be a requirement to reimburse. The service just needs to be correcting or ameliorating the problem.

CO-CHAIR WEISS: That is absolutely correct and it was moving mountains to get to that place.

MS. PERKINS: Yes, no kidding.

DR. JENKINS: And along those same lines, and maybe this is already implicit in just naming the overall outcomes like growth and development like Charlie did, but I'm looking for something that I think is much of an issue in kids than in adults, which is attainment of optimal functioning as opposed to an adult's where there's loss of function, that inability to attain what one should have had available.

I don't know how exactly to put that in, it's there kind of tangentially now,

but for kids for the same reason you're looking for maintenance, I think we need to be explicit about that.

CO-CHAIR HOMER: And I think that ties into the IOM report that was e-mailed around last night that sort of defined child health in the context of obtaining optimal health and growth. Ellen, did you have a comment?

DR. SCHWALENSTOCKER: Yes. I'm thinking of the National Priorities Partnership priority on coordination of care. And I'm thinking of things about receiving appropriate follow up and whether that would be a process measure or whether it would be a flip side of service utilization, but I'm wondering if we need something like that in there.

CO-CHAIR WEISS: Well it certainly would apply in the case of inpatient based screening and identification of disorders or conditions or whatever on which follow up is

required on discharge.

So again, I agree with you, I'm not sure whether that's process or whether that where it really belongs is in the EHR it seems to me. But it would be nice to be able to get at that transition and coordination of care issue.

CO-CHAIR HOMER: I mean my gut is that that's a process and we need to think of what the outcome is that that would be likely to address and it may be very variable depending on what the condition is and it may be a satisfaction or experience of care or duplication efficiency measure outcome as for the --

CO-CHAIR WEISS: Well just taking as an example hearing screening in the hospital and the child is identified through the screen as having a deficiency, but that's going to be picked up in the outpatient setting.

It's process initially in the

intermediate phase, but then what has to happen and who is the provider held accountable?

CO-CHAIR HOMER: So seeing as we do a lot of work in that area, the next level of processes was -- I mean the recommendation of course is that they be screened in the newborn they have confirmation by one month and you have definitive -- I think one month and definitive diagnosis by six months. I'm sorry or definitive treatment actually started by six months. So --

CO-CHAIR WEISS: So do you wait for treatment then and --

CO-CHAIR HOMER: So the question is what the outcome -- what's the outcome is that it's done each of those three things as a proxy. We actually had this intense debate at the U.S. Preventive Service Taskforce and fortunately we got them to reverse their findings on that.

Well I'll tell you, I mean that

the U.S. Preventive -- so the U.S. Preventive Service Taskforce viewed as the relevant outcome was employability, school function. That was the outcome.

The debate was sort of the quality of the literature that linked early screening to those outcomes and what ultimately convinced them was I think enough studies feeling that the bias involved in those studies didn't -- wasn't sufficiently strong.

So that's what got it to be a recommendation over time, but it really was based on the long term outcomes.

We made the argument, and we in this group can make the argument that for example parental satisfaction, which clearly parents are much more comfortable knowing that their child has -- whether their child can hear or not, but we made that argument.

And I still think it's valid. We did not convince the taskforce, at least at the time I was on it, that that was a

sufficiently credible outcome on which to base the judgement.

DR. WINKLER: just a thought, if your initial process is screening, the outcome -- the intermediate outcome would be treatment because if you didn't, you know, and then the treatment is an intermediate step towards the more longer term outcomes that you were talking about.

So perhaps you could make the argument for --

CO-CHAIR HOMER: Treatment by six months for example which is what the --

DR. WINKLER: Whatever it is, yes.

DR. DOCHERTY: Or another way to look at it, if you know, depending on where the service is expected to be, so when something is, you know, well known, a process is well known to lead to an outcome like screening we now know and it's been supported in the literature for decades that if you screen you get these outcomes, then doesn't

that process then become an outcome in a particular service.

So, you know, in these -- where the screening is supposed to be done, then it becomes an outcome for them not a process because it's supposed to be done there. We know it leads to this.

CO-CHAIR HOMER: I think it still gets down to the strength -- it's a balance of I think the strength of the linkage and then probably the feasibility and the time delay of the -- that would be my guess.

So for example, I keep hearing it doesn't seem reasonable that you have to measure whether somebody can have a job and graduate from high school, which was what the studies -- that's what the taskforce was holding, that doesn't seem reasonable to me.

But whether having, for example, a newborn hearing screen done, which is clearly a process is in itself a sufficiently -- would meet your charge for -- well probably for an

outcome measure if you're confident that that's going to -- use your microphone, I'm sorry.

DR. DOCHERTY: I was just going to say I would argue that for certain services it's an outcome then because we know that it has to be done in order for -- the process then becomes an outcome over a period of time.

It's like thyroid screening now, you know, for infants, it's now an outcome. You don't have to wait for the disease -- to ensure that quality care is being given.

CO-CHAIR HOMER: It wouldn't fit on our list so for example thyroid screens, that's an even clearer one that wouldn't fit on our lists that we could either modify the list to include it.

DR. WINKLER: I think what you're getting at is something much like Tom was talking about was proxies for outcomes like immunization rates because, you know, not getting something is really the outcome, but

that becomes pretty hard to measure.

So actually the receipt of the immunization, which is the protective element may be the more feasible outcome or proxy for the outcomes that you can measure and the question is, are there others of that ilk which I think puts us in the gray zone in terms between process and outcome.

And we may not have any of these measures, you know, it will just depend as we try and characterize the call for measures what we're looking for. We do need to kind of, you know, figure out where the boundaries are and that's what this conversation is sort of all about.

Personally, again, maybe it will come back to this. I mean my preliminary recommendation is that we not include those processes at the start and put out the call for proposals and see if we get things back, and if we get zero then we go back and sort of say, how about processes that you have a lot

of confidence in and come back.

CO-CHAIR WEISS: I agree.

DR. WINKLER: This is looking to sort of form the basis of the call, but I think there's more to it than that and we do want to talk about some other elements of it.

A couple of things, if you go down to the next slide Melissa, this was something that was brought up by members of the main steering committee that I thought were very interesting for you to consider and that is, you know, the source of information about outcomes.

And they really kind of boiled down to three, the patient reported outcomes folks, the world they live in, use this construct. And one is information that you get from the patient or caregiver. You know, they're doing the observation. This is sort of your history if you're the clinician it's like, you know, what happened, did you get better, can you do something.

CO-CHAIR HOMER: Or pain for example.

DR. WINKLER: Or pain, did your pain go away or can you do, you know, can you resume doing whatever it was you couldn't do and that's the reason you came to see me.

But the information comes from the patient. And then other information about outcomes could be clinician observation, an assessment, you know, decreased leg edema after instituting treatment, you know, diuretic therapy for your heart failure, whatever, any of those sorts of things.

And then the other outcome is more -- other type of outcome information would be physiologic which is something you could measure that is measurable by anybody, blood pressure, the lab result, whatever.

In fact, one of the interesting things that the IT folks are dealing with is where does data come from and it's conceivable that things like blood pressure measurement

don't come through a clinical per se, but come from the machine that someone took the measurement with.

So these are the more, you know, same thing with a lab result, so they're much more objective, physiologic kind of perimeters. And so the question would be is it desirable to have outcome measures that utilize all of those sources of information.

Because there are some people who feel like the patient reported outcome side of it, either too hard to do, too squishy, I don't know, something. But do you feel that all of those would be important to be sure we didn't, you know, deliberately exclude any of those as potential outcome information.

DR. RAO: Reva just a question, on patient reported outcome, does that include documentation by a clinician of improvement or is it directly collected from patients?

DR. WINKLER: I mean I think that would depend on how a measure could be

specified. I mean I could see it both ways.

I could see you documenting a series of standardized questions on like a patient with asthma, you know, have you missed school in the last three -- any days of school, have you done this, have you done -- you have a standard set and that would be documented in your chart, in your EHR easily retrievable data elements.

But it also could be a survey. So I don't think we're being prescriptive about it, but I think there are potential options for getting this information.

MS. PARTRIDGE: Reva, would your physiological include things like hospital admissions? Is that --

DR. WINKLER: I would imagine it's pretty -- I mean it's pretty -- yes, it's a fact.

MS. PARTRIDGE: Yes.

DR. WINKLER: Nobody has to observe or interpret it just is. Yes, I would

guess so. The group that does this uses physiologic and I always call -- I kind of think of it as objective. I mean just very fact based. I mean there's no interpretation necessary, it just is.

DR. PERSAUD: I guess I'd be reluctant to exclude anything because I think the way you get the information might not be telling you whether something's necessarily an outcome. As Charles point out, patient satisfaction surveys, and in the STEEEF the patient-centered perimeters are going to be patient reported, there is mostly. So I'd be reluctant to exclude anything.

DR. ZIMA: Yes. I struggle a little bit with physiologic because we've already talked about service use. And we might want to go back again to Donabedian roots and what probably call that type of outcome and absolutist outcome and which is kind of like the no-brainers, the concrete ones.

So vital signs, lab results, we've had some discussion about service use and, you know, is that the place we also put treatment adherence. So for example, you know, plasma levels of a certain drug, right, or Medicaid claims data. Agency data is not one of the data sources up there, should they consider that?

DR. WINKLER: Yes. I think I probably shouldn't have used the word data source as, you know, data stream, if you will. The question who's creating the information not necessarily how it came to you.

MS. PERKINS: This is Jane Perkins, I'm going to have to get off and go to this other thing, but I'll join you again in the morning.

CO-CHAIR HOMER: Thank you Jane.

DR. WINKLER: Thank you Jane.

MS. PERKINS: Thank you very much, bye-bye.

DR. LIEBERTHAL: I'm glad you

brought up asthma and the structured questionnaires because if you ask the patient, using asthma as an example, how's your asthma doing or how's your kid's asthma doing very often you'll get the answer, oh, okay no problem.

Then when you ask the specific questions, you find out there is a problem. So I would suggest that patient reported outcome needs to be by structured set of questions.

CO-CHAIR HOMER: And again, are we differentiating or would we elaborate on this to include families.

So again, I just think it's useful to do that and do we want to broaden, and maybe again broaden this to include other sources like teachers -- again if we're going to include school performance, for example, and then the other question is if we're going to include broader measures of public health.

Now I assume that most of those

data are still going to be coming either from the child or from a professional's observation of them, but it isn't necessarily the clinician. I'm sorry, David and then Tom.

DR. CLARKE: Well one thing that's not up there, and I'm not sure if it fits into one of the other categories is the various registry databases that exist. You know, this is clearly from my experience with data audits, it's not exactly absolutist, but it's not bad.

And so I'm not sure whether that is kind of a separate source or if that would be under clinician observed outcome.

CO-CHAIR HOMER: What's the input into the registries that you're talking about?

DR. CLARKE: Well it's a whole bunch of data cells regarding the patients hospitalization or surgery or all kinds of data and it's usually rather than clinician it's entered by a data manager.

DR. WINKLER: Well I think though

that the data manager would get any clinical data from the patient record which is clinician generated, with the exception of things like the lab results and the vital signs and the, you know, the more objective data.

So in those cases, because it's a large data set would probably be a mixture. So it's not meant to, you know, this was meant to be just an idea of keeping in the patient reported outcomes as well as the more traditional objective information as well as the clinician generated information and be sure that we all want to include that.

Because I think being explicit when we do our call for measures would be important.

DR. MCINERNY: Charlie, getting back to the school business, I think as much objective data as we could get, I mean you could ask a parent of a child with ADHD how things are going in school and the parents say

oh just fine.

But, you'd really want to see what, you know, what are his marks, is he getting 80s, 90s, 60s, 50s, what and you'd have to be a little bit careful.

DR. WINKLER: Okay. Bonnie, I think it's your turn. Yes, I just -- I think we've introduced Bonnie Zell and Bonnie is our population health expert at NQF. And so she wanted to talk a little bit about population and see how you all think that we might be able to bring all this together.

DR. BURSTIN: And just one more framing piece before Bonnie starts. I think that, you know, the child health piece in particular can get fairly expansive as you begin to think about outcomes, the point you just raised for example, about, you know, grades in school.

So I think we wanted to have Bonnie give what's intended to be an expansive presentation, perhaps to see where the limits

could be and then perhaps we could think about where we're comfortable having them for this project.

DR. ZELL: I appreciate that. I appreciate the opportunity to talk with all of you. I mean, when you're talking about children and you're talking about health, this is child health outcomes.

I think it's really important for us to kind of understand what we're talking about when we're looking at different denominators. And so I will address that as I go through this presentation.

But just to remind us when we're talking about populations and we're talking about health, what the definition of that is, and I think that we've touched on that in many of the comments that have been said here today, what are the boundaries exactly, what exactly are talking about.

And because we're talking about children who's level of ability to perform is

influenced from the day they're born and really impacts them the rest of their lives, it's really an important issue for us here.

What we're often talking about when we're talking about outcomes is disease. It makes a lot more sense when we do that for adults, because adults are a lot sicker.

When we're talking about children, it's a very small number of children that intersect with the health care delivery system with some kind of problem. So I think that's really important for us to remember and how do we think this through.

We do talk about children's health when we're talking about screening and developmental milestones, but then we very quickly jump to we're only now going to focus on disease focused outcomes pretty much.

So when we're talking about population health, the World Health Organization states that it's more than just an absence of disease, it's gone some -- a

positive aspect to it.

And the Institute of Medicine talks about that, but I just really want to point out at the bottom here that they state explicitly that it's a shared responsibility of health care, governmental public health and a variety of actors in the community.

And so it's very complicated to figure out where the boundaries are when we're talking about children. Next please.

So I thought it would be useful to just kind of walk us through, how does health really happen and what does it mean when we're talking about individuals and then when we go to population health, because really they're one in the same.

Health happens one person at a time, one day at a time, one decision at a time, but within the context of where and how people live. Not all of us have the same choices.

So it's impacted by where we work,

where we go to school, where we play, where we shop. It's influenced by the socioeconomic things that we always talk about, education, income, employment determined by the access to health foods, safe environments, available transportation and health care services.

But it doesn't happen primarily within health care, especially when you're talking about children. And it does happen within the context, as we were talking about here a lot today in terms of preference choices, cultural, social and economic frameworks and these individuals then aggregate to populations. Next.

And that is the only thing that a population is, is wherever we decide to draw the boundary around individuals, whether it's racial, ethnic, disease specific, life stage, level of poverty.

It can be all the different ways we'd cut it within health care whether it's a system of a cross systems by a health insurer,

a clinicians practice, a piece of a clinicians practice, just a segment, the diabetics, the adolescents, the newborns.

It can be geographic region, which also has a very big impact on health or it can be health care resource utilization. Next.

Just an important reminder of when we're talking about the determinants of health, especially when we're talking about children, it's important to think about those determinants that have the greatest influence in how we want to consider those when we're talking about child health.

Health care is estimated to have an impact of 10 percent, obviously these are not hard numbers and in some studies people go as high as 40 to 50 percent.

But clearly, we really need to understand the behavioral patterns, the social circumstances, the environmental exposure and where it is that health care falls, where other sectors fall and how we might need to

work together. Next.

This is healthy people in healthy communities. This is IOMs look at the future of the public's health in the 21st century and it demonstrates right from the center of this diagram, the importance of the conditions that need to be addressed for health, next, and the roles that all the different sectors play.

This is the chronic care model, which I'm assuming everybody here is familiar with. But this is the expanded chronic care model that really places the health system within the community in which it sits. And it's really important for us to remember that.

There are things that we do in the health care system that do not get done outside of the health care system that are critically important.

There are things that are done outside of the health care system that the health system itself does not -- the health care delivery system does not specifically

address, but many things that we could and many areas where we overlap and opportunities that exist that we can influence those things that we often don't that we also need to consider I think.

And I think that it's also just really important to understand that we do want activated, informed patients and families, but also communities and community partners. Next.

This is a driver diagram that was put together by a group in Wisconsin. I don't know how many of you are familiar with something called the Wisconsin County Health Rankings.

And these have been produced by the University of Wisconsin Population Health Institutes since 2003. They developed this driver diagram that if you look, there's health outcomes which looks at mortality and then self-assessed health status.

And then they look at the

different determinants divided up the way that I described them previously; the 10 percent health care, health behaviors, et cetera.

I don't know if you can see the fine print, probably not, but what they do is they just -- they break down what we mean when we're talking about health care. Here it's about access and quality of the outpatient care services, whether or not dental services are received, et cetera.

And you can obviously keep breaking all of these down, but it really emphasizes the significant impact that these other health determinant regions, health behaviors, socioeconomic and physical environment have and it goes down to the specifics to many of the things that we've been talking about here, high school graduation rates, et cetera.

DR. JENKINS: Was that intended for adults or for kids? I'm just curious if the breakdown is the same for kids as for

adults.

DR. ZELL: I would say this was really done for populations in general. It's a community health index, so it definitely has indicators in there for children such as things like graduation rates are in there, things about health education for teenagers, et cetera.

So it definitely has indicators in there. I wouldn't say that it's got everything by any means, but this is something that we're going to be working with as a beginning in the National Priorities Partnerships for the population health community health index, which is something else that we can talk about.

But I think what's really valuable about this process that they've done is that it's been recognized as something that is really gotten county level attention within Wisconsin, has motived a tremendous amount of intervention, discussion and action.

Because of that, Robert Wood Johnson Foundation funded them recently to do these county level rankings for every county in the United States. That will be released in February of 2010.

What's important to know about these are they -- it's a very powerful process in that it has garnered a lot of attention and discussion, but when you're talking about action, everything is local.

And we really need to take this county level information and understand that we need to look at this from a population standpoint, we need to bring it down to neighborhood and community levels so that we know what to do where, because doing it in a blanket fashion everywhere is not the best use of our resources we need to target. Next.

So defining population relationship to health care, I thought it would be useful just to talk a little bit about how to bring population level

assessments into health care.

This might be things like querying the health care data that we have to understand populations. For instance, saying what percent of our patients have X problem in our practice and what percent are getting all the things that they need. And I'll give a couple of those examples.

But I -- my background is a nurse and then an OB/GYN physician for 20 years and practice at Kaiser in California and never once did we ask that question when I was there. I did not have any idea how many patients I had with a specific disease or a specific age breakdown, how many women at mid-life did I have that might need X et cetera.

So it's a very powerful way to just look at our own data. It's not hard to do, it's data that we're already sitting on, but it really gives us a very different view of what to do rather than waiting for just individuals to come and knock on our doors.

What is it that we need to do proactively for the populations that we serve? Another is to utilize publically available data to better understand community context and populations by using some of the tools that we have now such as GIS mapping.

So taking those same individuals, plotting them out on the map, overlaying that with some of the publically available data whether it's looking at asthma patients and air quality et cetera. You can do this -- there's over 600 layers of free publically available data.

And I'm working on some projects to do just -- that have just demonstrated incredible power. We're looking at congestive heart failure patients in one health system in Atlanta and just by asking questions that we had not asked before, we learned just amazing things such as some people had been admitted 20 times in three years.

But because it was just patient

was readmitted and we hadn't asked those types of questions. So, what was amazing to me is I posed a list of 20 questions that were really -- provided a lot of insight in how easy it was to query their data to get it.

It was just by ICD-9 codes and all these things would popup. So it's a different way to -- it's a different lens to look at what we do. Next slide please.

And then, you know, again when people talk about well that's health care, that's individual interventions versus that's public health, it's really a matter of understanding that there are both individual level strategies and interventions and there are population level strategies and interventions and how to bring some of those into health care.

So for instance, if you've done a query and you understand your population, whatever that -- whatever way you've cut it, you could do targeted outreach for screening

and follow up instead of these blast things that we do, we could really target what we do to specific segments of the population so that we can, again, utilize our resources in a much more efficient fashion.

Suggest available community level health care and health promotion resources targeted to specific populations.

Again, when we're talking about health care versus where these fuzzy borders are, there are a lot of opportunities for health care to disburse itself into a community to provide health related services that are still considered health care in a sense, but really impact health on a different level; disseminate newsletters, provide healthy recipes, partner with community stakeholders, schools, businesses and faith-based et cetera. Next slide please.

So, in addition to assessing did Alissa get her peak flow, her home management plan and a corticosteroids prescription, can

we also ask how many individuals that we care for in our practice have asthma and what percent of our asthmatic patients have had the peak flow over the last 12 months of home management plan, et cetera composite measure. Next slide.

I think it was really interesting some of the conversation that's happened earlier today where a lot of these types of issues came up and I just thought I would put some things up there that might give us something to think about in terms of conversation in thinking about where the boundaries are again.

So here's looking at prevalence of obesity among U.S. children and adolescents aged I think it says 2 to 19. And it's broken down by different ages on the bottom and it shows you what's happened.

This is NHANES, which is a federal program of evaluation across the United States, and it shows what's happened from I

think 19, I can't see it myself, but it's like, okay so 1971 and the last is the 2003 to 2006 NHANES shows you what's happening by age and over time.

And clearly we have been, you know, we in health care, we measure BMI, we might suggest to parents and educate them about what kids should eat, educate them about exercise.

We might be able to check those off and get really good scores in health care, the question that we have to ask is how far out do we go and how do we work with other sectors to make sure that the conditions exist so that the things that we're suggesting are actually doable.

Meaning, is there access to the -- let's talk about kids, in schools to healthy foods, recognizing that we're talking about health care, but if that's a concern of health care and if child health is a concern of health care, where do we draw these

boundaries.

What can we do, doesn't mean we have to necessarily be accountable for what goes on in schools, but can we have joint accountability with schools or can we work with schools to make sure that they have the meals that they need to have and the physical exercise, et cetera. Next slide.

This just shows what's happened over time from the NHANES 1988 to `94 and the next one which was 2003 to 2006 to again show the need to look at things from a segmented fashion.

This is looking at the difference between boys and girls and the difference in race and ethnicity and you can see that there's a huge difference in both. Next slide.

So as I already posed, should other sectors in the community that significantly influence health status in addition to health care have accountability

for health in their communities, and if so, how might we connect performance measures in health care with activities in other sectors? A question just for us to talk about.

School nurses, I met a school nurse at a meeting just over the weekend who was talking about their interest in working more closely with health care, their nurses and the issue of community benefit and how community dollars are spent from hospitals, non-profits being required to spend a certain amount of money in community benefit.

Is there an opportunity there to think about how health care could get involved in these types of issues? Next slide.

Can we expand our frame, and you're working on your framework from why does this patient have this disease at this time to what population circumstances are the underlying causes of the disease incidents in this population. Next slide.

This is just a graphic just to

highlight that what we're focusing on is over on the right. So when I talked at the beginning about childhood -- the denominators we're looking at, I think it's really important that we just think about when we're talking about child health, the denominators we're talking about.

Because when we're talking about children in general and doing the screening and the milestones, we're talking about the entire population. When we're talking about those afflicted, we're talking about that just those on the right-hand side of the diagram.

And what we have been talking about a lot in general in terms of health care and health is moving us upstream towards prevention and so really trying to think about what that means operationally and what that means we might need to think about in terms of the broader issues.

And the importance, I think, of really emphasizing that public health network

meaning, public health governmental public health, that's schools, business, in a broad sense and public policy, city planning as well as the health care delivery system have some areas where they have distinct roles, but very large areas where there's tremendous overlap. Next slide.

These are just some references that I put in here. The Association for Community Health Improvement is part of the American Hospital Association that did an excellent steering committee report on hospital's role in communities and their role in the public's health with many suggestions of what could be used, what could be done from a health care standpoint and a lot of information there about what I mentioned before using community benefit dollars.

The U.S. Preventive Services Taskforce is a resource that talks about community level, population level interventions that have been demonstrated

through science to have impact.

So for instance, there was one study in that in 14 out of 14 studies that demonstrated that those schools that had moderate to vigorous physical activity mandated for kids, 30 minutes, at least 30 minutes a day had absolute decrease in BMI, they all had improved aerobic fitness and it went to the issue that somebody brought up earlier in terms of maximal function.

So there's a lot of different tools here, I thought I would just share that had a lot of different interventions, guides, ideas, et cetera. But I do think it's important when we're thinking about outcomes to think about health outcomes as well as some of the outcomes we've been focused on. Thanks very much.

CO-CHAIR HOMER: Thank you Bonnie. Tom?

DR. MCINERNY: Well of course, the Massachusetts has instituted a couple of

changes and I'm not sure whether they're improvements or not, but certainly universal health care for everyone and how has that affected the health outcome of children. I don't know if anybody's looked at that and where they are with that.

And then the other is the mental health project to divide the state up into six regions and provide consultative services for the primary care physicians and I know that's two or three years old now and I'm not sure what the health outcomes of that has been either.

CO-CHAIR HOMER: Two good questions. We could find out more I think short answer on the health insurance, again, we had relatively low health uninsurance for kids before the expansion, we now have even lower. I think it went from -- but it already was quite low.

And I think in terms of health status, I don't know. I don't think we've

seen the health status effect yet. Mental health is a good one, there was both that and then there's more recently what's called the Rosie D. Settlement which is an even more expansive mental health program.

But to be determined. We'll send Reva home to do some homework and see if -- no I don't think there are yet any measures of impact of those societal changes.

But those are largely, to Bonnie's point, those are largely health care service changes rather than some of the broader changes that her report was at least suggesting we bring on to the table for consideration, you know, which would be more, again to use the parochial Massachusetts approach.

Massachusetts also launched what they call Mass in Motion which is more about in addition to providing health services it's, you know, getting the wise involved and building more sidewalks and changing school

lunches and, you know, all the broader array of interventions that are going to address the particular issue of obesity. Donna?

DR. PERSAUD: Thank you. That was an outstanding set of slides that I would like to borrow is my first request if that's possible. I really like the integrated way that you have the concepts listed up there and all the resources.

And I think that I guess being the prevention minded pediatrician it's an interesting thought to come up with joint accountability for measures.

And if it's not even in scope for what we're supposed to do, I think we have to acknowledge that some of our limitations might be because we're not getting to joint accountability.

And some of what I talked to in our community care we realize that the obesity epidemic is such that the answer is not going to be find every child a doctor and get them

a check up every year. It's going to be joint accountability with other entities.

So it would be neat and maybe that's the future of this to begin to use those concepts in the conceptual framework. And I am actually coming, I don't know where we'll be doing the conceptual framework brainstorming, but I've got maybe a 3D idea in my head coming up that it's not going to be flat, it might be 2D I think there's a chance it could even be 3D.

DR. ZELL: Could I comment on that??

CO-CHAIR HOMER: Please.

DR. ZELL: Because I think that what you're bringing up Donna is really important that I think, and I'm not sure what the answer is, but I think we tend to try to boil things down to something very simple and linear and in fact what you're saying with three-dimensional I would call complexity.

It's very complex and especially

when you're talking about child health. I think we have to understand the complexity of it and all these different factors that interrelate and somehow acknowledge that.

And I think be explicit about where we're -- I mean if this group decides that it's just really health care focused on the traditional sense, I think it should be stated so explicitly.

DR. JENKINS: I want to echo what Donna said and thank you very much for that presentation and it was a little bit what I was alluding to before about this population based health.

But I guess I have a question then for Reva or Helen, again related to scope. I was making the assumption that these were going to be NQF endorsed measures of health care but I heard you say at like the very beginning that NQF also has a priority setting for health over all mission.

And is there anyway that this

process could perhaps influence that priority setting process rather than just the measurement endorsement or is that out of scope for us?

DR. BURSTIN: No that's very much within scope. The National Priorities Partnership has already identified population health as one of the six national priorities and within that delineate a real focus on preventive services screening, healthy behaviors and this general concept of sort of a community index of performance.

I think there is a very open question as to whether over time there is an expectation. Perhaps we'll get some measures for which accountability can't be solely laid at the heals of the health care system. And it may be now.

We've already, for example, endorsed the set of AHRQ prevention quality indicators which indicate preventable, potentially preventable admissions of a

community. They're community level indicators and it's very hard to specifically assign accountability for whom that, you know, that admission could be potentially related.

But at the same time, there's a recognition that's an important quality measure for us at the community level. So I think that's what we wanted to bring to you, get your sense of it.

I mean, you know, as Bonnie and I were talking about this, she clearly goes further than my comfort zone, but this is where she lives. But, you know, I think there may be measures where we were beginning to see some coalescence of some of these different sectors coming together.

And I think especially in this group, it's hard to imagine you wouldn't want to consider schools as a logical locus within which, at least for me it's the interstices, you know, can you at least think about measures that maybe get us closer towards

understanding those linkages, those connections those opportunities for collaboration that could improve kid's health.

DR. PERSAUD: Actually just very quickly, the last mock Joint Commission survey we had, the surveyor came in and asked us whether we assessed cognitive and academic performance of children with asthma to help them in their self-management.

And that would be a great example of how that circular where your health care is going to effect their ability to handle school and their ability to achieve in school is going to effect their ability to manage their medications and their asthma action plan, so.

DR. JENKINS: I also think laying out a complex framework is actually protective about inappropriate use of measures in certain -- at context.

Just to make the point in Massachusetts, we've had bitter battles with our major payer over whether or not

pediatricians could be held accountable for reductions in rates of obesity or whether that's beyond scope of what they can legitimately be accountable for.

And so if the whole framework was laid out, it will also be protective against inappropriate use of measures. So far they've rejected the opportunity to be accountable, but just barely been able to make it through.

CO-CHAIR HOMER: The thing is the payers wanted to hold the accountables -- the providers accountable --

DR. JENKINS: For reductions in rates of BMIs and actual improvements towards normal and the pediatricians have marketably rebelled against having money on the table for that because they do not believe they can influence it.

DR. ZIMA: This is the first time I've met another Dr. Bonnie Z. MD, MPH and it's amazing because, you know, we struggle so much in child psychiatry because how much is

child psychiatric care responsible for things like recidivism, out of home placement, child abuse.

But if you look at some of, particularly in California, the state funded legislation for mental health, those outcomes are in there. And I think one of the examples right now we have is the California Mental Health Service Act where mental health dollars are being justified to reduce things like homelessness.

So I think that, you know, from a psychiatric perspective, this whole idea of joint accountability, we desperately need some help because right now we are using mental health dollars with the assumption we're going to improve those outcomes.

CO-CHAIR HOMER: I personally think that's certainly in our scope to at least -- I think we definitely need to look broader than just academic performance, but look at those issues like recidivism and like,

you know, jail rates or whatever the -- incarceration rates, that's the word I was looking for and those to violence, youth violence, a variety of things that are outside the typical scope.

DR. ZELL: Has everybody else had a chance?

DR. WINKLER: I think one of the things that when we do this call for measures when we look at potential measures out there, considering the population focus, if you look at the measures we've already endorsed, there are quite a few of them who's denominators are per 100,000, all right. So certainly NQFs been down that road before.

And the question would be, you know, to what entities can that be applied? Does it have to always be geographic, which is sort of the traditional, but could you apply that to a large health system? Could you apply that to a health plan? Maybe not the smallest, but the other, so and why not.

So that it's sounding, from your comments, that the kinds of measures, the kinds of what we call population measures where you have the denominator is something like per 100,000 or per 1,000 or something like that, would be measures you would want to consider.

Would you want to keep in the box as opposed to exclude them, though they will have their limits and their applicability can only be, you know, might be different than some of the more traditional ones.

But are these important outcomes that we need to have within our framework and within our set or our hoped for set, or our ideal set? Yes, yes, yes? No, no, no?

DR. ZIMA: It's interesting because I think that it depends on who's paying as far as sort of, you know, the outcome that we want to improve.

I think, you know, Medicaid public mental health it's a little bit easier to go

down that slope because it's all public dollars and then we talk about cost shifting and that we've kind of justified mental health services because we ideally reduced cost and probation or something like that.

But I don't know -- I mean it raises sort of another level of complexity about when the responsibility in a privately insured company is not owning responsibility for the societal outcomes.

DR. WINKLER: But wouldn't they be responsible for their population of enrolled or folks that are part of their system as a population.

And that I think was a lot of what Bonnie was talking about was, you know, not just who walks through the door, but if they're part of your group, define the group however you want, but if their yours, do you have accountability for the entirety of the group and not just the active ones?

DR. ZIMA: I think that's a good

question.

DR. PERSAUD: I think what you said with, you know, as long as we define the limits of applicability of the measures and I, just speaking as an end user and knowing what's going on in the communities, I do think more and more coalitions and communities want to galvanize resources around what should be the benchmarks.

And I think I'm hearing, and I am one of the needers of those kinds of measures, but I do think we should be very prudent about defining the applicability and the reasonability to, you know, who's using it and why.

CO-CHAIR HOMER: Do we want to try come up with a threshold, I mean it's -- there are no data on this, but do we want to come up with some threshold of proportion of, you know, attributable risks or accountabilites. So for example, your BMI in Massachusetts, you know, could we reasonably attribute to the

health care sector, you know, X proportion of accountability?

I mean, on the smoking -- so for example, on the smoking issues on the adult side, so for example, obviously people are -- plans are held accountable for counseling about smoking cessation, are they held accountable for the proportion of the population that smokes is I guess the next questions.

I mean, that's a held behavior. I mean that's the kind of stuff, never mind lung cancer rate as a preventable outcome measure. Because I think that would probably be along the lines of what we're talking about.

DR. RAO: How about some case studies as to how each measure should be used, like a little paragraph that follows them. For example, you know, smoking rates in this health plan happen to be this much, this is what the health plan actually did to change them or to enforce them in a positive way.

CO-CHAIR WEISS: I honestly I'm seeking information here, I honestly don't know the answer to this. Are there studies that we could look to that would give a sense of what compliance rates for various of these measures would be? Average by cutting it by type of population or region or whatever?

DR. WINKLER: Marina, one of the things we ask for in the measure submission is that sort of data. And even those that provide us with a large amount of data actually it's relatively limited to -- your question was extremely expansive.

I mean I'd love to have, you know, wide ranging data on all sorts of things and stratify them in a 1,000 different ways, but that's very rarely available. So to the degree data is available, usually whoever the measure developer is, they're using it for whatever their purpose in developing the measure was and they will have applied it to that group.

Sometimes it's big, and sometimes it's very narrow and it tends to be somewhat variable. Whether there's additional information, except in some of the large measure developer activities where they publish as a result of some of it, it's really hard to find. And if you all can help us with that, that would be grand.

DR. RAO: But Reva isn't one of the criteria for submission -- a basic criteria for submission of a measure is that they have to identify a significant problem? You can't put in a measure, for example, where everyone's, you know, giving out influenza immunizations already sort of --

DR. WINKLER: Well they can submit it, but it should fail on, you know, some of the criteria in terms of usability, in terms of importance around is there a gap and variation in care, is there a quality problem associated with it. So they can submit, but it would have struggles against some of the

criteria.

CO-CHAIR WEISS: Well let me just suggest then that maybe we would like to think about this by changing the paradigm a little bit and maybe instead of looking for someone to hold accountable in these areas where it's an entity, an organizational entity to hold accountable where it's iffy, maybe we put this issue of measuring true outcome in the basket of items on which we would like to see additional work done, I mean.

DR. LIEBERTHAL: Charlie mentioned the idea of apportioning to the health care system part of the outcome and I think that's a very slippery slope because I don't think there's any way to collect data that would be applicable.

However, in using outcome data for things that are primarily health care related, take asthma, again, using the asthma example, by comparing organizations or health care systems against one another, if they're large

systems and using risk adjustment factors that may be quantifiable, it's the comparison that becomes the measure.

So, for example, Kaiser with its asthma rates and we do have, Bonnie, I don't know when you left -- were you in Northern or Souther Cal? Northern. I think you have some of the same systems as we have, but we have some very robust systems for measurement, population measurement that can be broken down by medical center office, provider, et cetera, et cetera.

How we use them is another story for using them robustly or not. However, if you have a measure that is a valid measure and you put the Kaiser Health System up against United Health Care and against Blue Cross, et cetera, et cetera, now you have a comparison against which health care organizations can be compared.

And then if you make this public, as is done with HEDIS measures, you now have

a basis for consumers to pick the health care so the incentive is if you do well on the measures then you will be more successful in an economic and business sense.

You could even stretch this to school systems again using the adjustment, what is the obesity rate in a school system and what should a school system be doing to deal with the education or break up any comparable populations and compare then against each other. So this is one way that measure, outcome measures could be used.

DR. BURSTIN: Just one additional thought, this is really interesting. If you actually look through the National Priorities Partnership and you go to the population health goal, for example, the goals themselves are quite broad and intended to be so.

So the three under population health is all Americans who receive the most effective preventive services recommended by the taskforce, all Americans will adopt the

most important healthy lifestyle behaviors known to promote health and the third is the health of American communities will be improved according to a national index of health.

So they are far reaching and that's the intent. And I think what we're trying to get at is, there may be a set of measures that are the best measures we need to move the nation's health.

I think what you're kind of getting at Kathy is there are issues where the accountability locus isn't always clear and assigning accountability can be complicated, but it may still be that a measure that looks at the reduction of obesity in a community or in a accountable care organization or in a public health system is very appropriate.

But I think the key thing is thinking about what the appropriate level locus of accountability is, but still the right measure we should endorse should still

be the one that gets us to the right place.

DR. ZIMA: So question, because I think when we talk about joint accountability there's also that whole problem with data sharing and data linking across the sectors.

So in thinking, you know, when you say, okay that's a future research agenda item, when we start thinking about the measures, should we also be identifying other data sources that would require linking in order to measure that outcome?

CO-CHAIR HOMER: We have the privilege of not actually having to develop the measure. We don't do any measurement development here, so we -- but we do need to -- I think the question is, who would we be soliciting and eliciting measures from?

DR. ZIMA: It's an exercise because it nicely kind of stimulates I think, you know, Marina says, okay let's put that on sort of the future agenda, you know, that these are things that we think are important

like recidivism or reduced foster care placement.

But is that within the scope of this committee to sort of at least identify that oh, that would require data linking that right now existing health care data bases aren't allowed to do for HIPAA or whatever?

CO-CHAIR HOMER: I mean again, typically what would happen would be we could identify a whole bunch of things and then either ourselves opine about what would be needed for it or that often would lead NQF to create some workgroup that's going to elaborate on that. I think that's what happened on the care coordination process.

CO-CHAIR WEISS: Another way we might go, for example, is to do a spreadsheet and on the far right column say, this particular measure lends itself to a population wide reporting system. So we could flag it and say this has -- this particular measure has added value in the population wide

arena.

CO-CHAIR HOMER: Why don't we take the two questions that are on the floor and then I think we're due for a break. So Tom and then Lee.

DR. MCINERNY: On the population thing, I think one of the most important lessons that we need to get across to physicians and providers is to measure the health of their entire population of patients.

All too often, you know, we ask the physicians, you know, how's your immunization rate, oh it's great, 90 percent of my patients are immunized. But then when you ask them to actually go and look at all the patients that are in their practice, oh gee, you know, these kids, I don't see these kids very often and they don't have a very good immunization rate.

And then all of the sudden, whoa. And unfortunately, it's the rare practice, in my experience unless maybe in Kaiser or some

other program like that, that has a clue of how many patients they have and how well immunized or how many patients with asthma they have even and how well they take care of them.

You know, if you ask a pediatrician name all your patients with asthma, they can come up with three or four and then they start to wonder, gee I don't know.

And that's a big, big problem and I think trying to get that message across that you are responsible for a population of patients that are registered with you and you really have to know what's going on with all of them and have to reach out to them in some way, that would make I think, may make one of the bigger differences on population health.

CO-CHAIR HOMER: And again, because the audience for NQF is broad and may of the users are plans who actually do have a defined population and efficient practices,

but it's good. Lee?

MS. PARTRIDGE: I'm just feeling a little confused. Are we talking in the population health context of inviting outcome measures be submitted for our consideration that are things like incidents of carries among -- of children under the age of 12, is that what we're talking about? Because we get -- I think we're going to get a lot. Well, whatever.

CO-CHAIR HOMER: I said then that will slide us very quickly to the Healthy People 2020.

MS. PARTRIDGE: Well yes, it kind of looks like that. And yet I absolutely appreciate the relevance of some of that kind of data for galvanizing activity in the health community and in the community at large.

I mean I picked the dental one because it happens to be a very difficult one with respect to low income populations. And if you -- except in the state of Oklahoma

which -- I mean Utah, which bars fluoridation of water, it's usually an indication of lack of access. But I just wondered how big are we here?

DR. WINKLER: Well ultimately that's the question we're posing to you and as Lee mentioned, if we don't put reasonable boundaries, we're getting more than we can handle. So trying to find where those reasonable boundaries are for the work and the people and us to do in the time frame is the realities we have to deal with.

There's a lot -- there are tons of things you can do, but the question is how do we define it in a way that is appropriate, but doable. And so I'm not the one to answer that Lee, you are. But it's a very appropriate question to put out for folks to consider to help us define where the edges are, where the boundaries are.

CO-CHAIR HOMER: So what I'd like to do is to call for break and give us a 15

minute break. Let you mull on these as well as return a few phone calls and use the facilities. We'll return in 15 minutes and then try to come to some level of closure around this topic.

(Whereupon, the foregoing matter went off the record at 3:14 p.m. and went back on the record at 3:44 p.m.)

CO-CHAIR HOMER: Well we gave you a little more time during the break so that you could figure out all the answers in your small group discussions and come back to the group with it. Again, my sense from the previous discussion was productive and broad ranging conversation.

I detected a fair amount of enthusiasm at one level for considering broad measures of population impact with an undercurrent of anxiety about both the accountability and the flood gates that that could open in terms of the response. That's

kind of my take on that conversation.

So I think what we need to do is come to some closure in the next 45 minutes or so with what we would like -- what we'd really like to put as the scope of the call for measures.

And one thing maybe to start with, was it -- who had said they had in their mind a multi-dimensional matrix?

CO-CHAIR WEISS: Donna.

CO-CHAIR HOMER: Donna. Did you - -

DR. WINKLER: 3D.

CO-CHAIR HOMER: 3D, would you like to start without putting you on the spot, would you like to start by framing that up?

DR. PERSAUD: So I'm drawing over here in looking at Bonnie's slides. I guess what I'm kind of thinking is that growth and development might be the permeating concept across many measures.

And I'm starting with this one

sentence in one of the early documents that says in the most global sense that a child -- a health child is one who has transitioned well from fetus to adulthood. And I like that transition because I think that that's very foundational for pediatrics.

That's what the development defines as separate than all other speciality lines, probably development and family.

And so I'm thinking that I would like to have growth and development somehow permeate through all the measures, at least on an assessment level that when we're looking at them we're in or out; are you, you know, does this measure for ADD, for asthma where's growth and development.

So that's sort of one trajectory going on. And then the other is that there's growth and development one way, but at any point while you're growing, whatever's going on around you in the environment is affecting your ability to make that transition, right,

whatever is going on in the school, public policy, media, et cetera.

And where I am is so how does this 10-40-40 rule fit in, which is the 10 health care, 40 behavioral, 40 or 30 genetic. And those three constructs are in my head as, you know, what's the way to graphically represent those constructs.

And the last point I have in my head is that let's maybe not try to be perfect, but come up with something that we think makes best sense that we can all live with, but that is somewhat forward thinking and might help to move the profession forward in terms of being able to accept and deal with the complexity because I think that in part what's going on.

There's a depth of growth and development and then there are the snapshots going on of what is the context of the community and the individual versus population. So, I think after I sleep on it

I might have some kind of drawing. But that's my thought.

CO-CHAIR HOMER: Any other thoughts how to build on that? Tom?

DR. MCINERNY: Well I think it's always a good idea to sort of think about who our audience or customers and I guess certainly HHS and CMS would be kind of the national level and then I think about health plans, the insurers or health systems, again, going down one more level and then eventually down to providers, you know, provider systems, practices, which is a smaller level.

All of those people will presumably -- the measures will be -- they will be applied to them or they may wan to use the measures one way or the other. And so we need to think about making measures that are useful at those various levels.

CO-CHAIR HOMER: Agreed. So the -- I wouldn't say tension, but I love the idea that we're going to move things forward and be

forward looking. I think we should also realize that for this to be picked up and used probably should build on some of the reasonably successful frameworks that are out there.

I mean Kathy you already mentioned the STEEEP one, safe, timely, effective, efficient, equitable and of course we should call it STEEEF because it should be family centered. So that's one framework and I think we should be cognizant of that and use that as a potentially dimension.

I mean another one, just to state the obvious, but it's the acute care, the chronic care, the preventive care and much of what we talked about was preventive care.

And sometimes with the fact framework they use sort of palliative or end of life care as the other dimension or sometimes even transitions. I think maybe as a euphemism that they use but maybe for us transitions might have a broader framework.

I think we shouldn't shy away -- I mean from an age based -- I mean the easy way to force the capture of developmental issues is to say deal with age and again it makes sense to at least get people to think about measures and basically the usual categories. I mean, infancy, preschool and we can argue.

But, you know, base is zero, one, you know two to five, school age which is 6 to 12 more or less and then adolescence, which is 13 to I better say 21 or the AAP and NACHRI and all those other people will shoot me. So we should write the AAP certainly. Those would be reasonable things to do.

We need this developmental context. I mean before I saw your list of outcomes, I mean I was in clinical, functional experience of care and then developmental with the usual cognitive, emotional, social and physiologic characteristics.

So those are lots of dimensions, but I don't -- I think it is a complex world

and I don't think we can shy away completely from that complexity. Kathy?

DR. JENKINS: What I'm wondering about and I keep thinking back a little bit to some of Bonnie's slides if in terms of an overall depiction there was some slide where there was the community, contextual, the big cloud with all the complexity and then the blue got like a little bluer and it kind of focused down more towards the health care component.

And that was a good one too, but the combination of the triangle one plus the cloud one, but that one --

CO-CHAIR HOMER: The chronic care model, yes.

DR. JENKINS: Chronic care model, okay sorry I thought she just made that up. But anyway the point was that I was thinking was we could put out a call for both kinds of measures wherefore the broader blue asks specifically for population based measures of

overall child health that could potentially be useful to guide public policy around improving the health of children.

And an interesting framework for that might be something like the multi-dimensional WHO definition of health or something comprehensive.

And then for the health care system, ask explicitly for measures related to child health that have a high component of actionability and attribution by the health care delivery system.

And then I'll go back to what I said before which is we have found, and I must say one of my colleagues kind of put this forward how incredibly helpful it's been to use the Institute of Medicine six steps towards high quality care. It's just worked way better than I ever thought it would to hang the ornaments on the tree.

But just so you know what we found is that for many of the criteria we could find

whole system type measures, but for the effectiveness domain we had to go one disease at a time and we could never get away from that.

CO-CHAIR HOMER: And I was just going to say, the National Quality Report certainly uses those dimensions matrix with basically ***3:54:32 and the fact, you know, living with illness, getting better, staying healthy, end of life care framework.

So I think that for the health care setting with a developmental context I think would probably work reasonably well. I personally like your idea of soliciting that as a distinct -- right, soliciting both but articulating it as a distinct call or a distinct component of the call and considering those kind of as a group.

DR. WINKLER: Two, sort of more two types of things to differentiate them so that people don't get muddled.

MS. PARTRIDGE: But Reva, where

the developer can point to specific links between the two, that will certainly strengthen their position vis-a-vis our judgement, right?

DR. WINKLER: In terms of the population measures, I mean we're still talking the context of outcomes, right? Yes, okay, just making sure. Just checking. Let's not range too far, there's only five of us.

DR. BURSTIN: I just want to make one other point actually just to give you some, perhaps some comfort. When the measures actually come to us they all have to complete, and Kathy knows this, a very detailed measure submission form.

And so they're going to already have to up front indicate the level of measurement or analysis for the measure. And so that could be individual clinician, facility, intermediary delivery system, health plan or community or population.

So just to keep your mind -- so

there may be measures that will come in that will be very appropriate or community population level like those preventable quality indicators we endorsed through AHRQ, but there may be some that would fit better at the clinician level.

So you can have the wide range and specifically indicate that this level of analysis can be a very important consideration for the steering committee as those measures come forward.

CO-CHAIR HOMER: And the importance criteria specify the link to the -- I mean they will have to at least articulate how there's a link between health care delivery and broader outcomes.

DR. RAO: Reva, just a question. In the past for measures have individual clinicians just submitted measures even if they're not affiliated with the organizations?

DR. WINKLER: Yes, it's not he most usual, but yes occasionally, often

academics. Kathy are you an individual when you submitted yours?

DR. JENKINS: We submitted on behalf of Children's Hospital Program for Patient Safety and Quality. But I do know that other people have just worked hard to make a good definition and send it in. I don't know how it's been received at NQF.

DR. WINKLER: It's not the most common, but certainly there's no reason not to do that if you know somebody who's doing some good work. What we're planning on doing is all the things you've brought up today, we're actually going to spend the rest of the evening looking for some of this stuff, we're going to bring it back to you tomorrow.

Hopefully we'll have some of these lists and some of these ideas for you to refer to. The things you've brought up in terms of I'm going to remake that one slide with your recommendations, we'll see as sort of a next draft, I mean you can play with it again, and

we'll see if it's working for you.

We'll, you know, try and develop some draft or rudimentary ideas of how we might combine some of these dimensions in terms of plugging in some of the existing measures and how -- and see how that might work for you.

One of the problems is, the only way we can display it is two-dimensionally so we might have to think creatively and sort of in your mind build the third dimension or the fourth dimension or whatever dimension you're working in.

But we'll see if we can kind of draft up some of these to give you a sense of what these might look like and see how you react to them.

And that's what the plan for kind of tomorrow morning is, see if we can organize some of your thoughts into, you know, what we've heard and kind of format it up for you, give it back to you and give you a chance to

say that's not really what I meant, maybe it sounded good but didn't really look so good now, can you do this, that or the other thing.

So it's a working together to get some of your immediate feedback. But we will be looking to draft the call for measures, you know, the meat of that and as well as this sort of framework idea of creating a way to describe what we're looking for in child health outcomes.

And we'll use as examples the existing endorsed measures to plug in there and ask, you know, is this working, plus the idea of let's flag the population health measures, we can see if we can do that, we can give them a gold star or something and see if we can put some of these into play and see if this is working for you.

If not, we can, you know, we can go to plan B or something. So what you've done today actually has given us the tools to try and synthesize it a bit to present to you

tomorrow to allow you to refine it, revise it, scrap it and start over, whatever it is that works for you as part of this entire process of you guys being able to present this not only to yourselves, but to a greater audience to understand how an approach for looking and measuring child health outcomes.

So questions about where we're going?

CO-CHAIR WEISS: I have one quick question. Tomorrow when you present to us Reva, is it your thought that you would lay out kind of a draft of the call for measures, is that the idea?

DR. WINKLER: Certainly the meat of it, you know, there's all sort of boilerplate that goes fore and aft, but yes, the actual we are looking for measures that.

CO-CHAIR WEISS: Right. I've got sort of two suggestions that I just want to offer up and they just may be redundant to what you're thinking already, in case not.

The first is to make it abundantly clear in the title that outcomes is the focus and then to define right up front what we mean by outcomes or whatever you think needs to be taken into account in making that judgement call.

DR. WINKLER: Okay. Other suggestions? Now's -- jump in.

DR. MCINERNY: More of a question. When you send out the call for measures, typically from what organizations do you get responses?

DR. WINKLER: It really is across the board. I think this summer we pulled together all the measure developers who've submitted measures over the years, we're trying to update their information on how -- and working with us.

And it's over 75 organizations that are currently on our list, but we know there are others, especially in specialty areas like children. There might be folks out

there that we really haven't, for whatever reason, come in contact with and that's why we're looking to you, all for your context out in the child health community.

So, but, you know, we do a lot of work with NCQA, we do a lot of work with the Physicians Consortium, the Joint Commission, who else is doing them, STS has been a lot of our measures, CMSs, NACHRI has done some, I mean, you know, AHRQ, those are the big ones.

But we've had some, I mean like Charlie said, he's got one of the measures on BMI is from NICHQ and so sometimes it's only one or two measures from an individual developer.

So, you know, it's across the board, but we're always looking to increase our list so that whenever we put out a call, we send it to that group as well, and you know, we just want to keep building that list to stay in touch with all the folks out there who could be in the measure development

business.

DR. SCHWALENSTOCKER: Reva, I think sometimes I've seen you put sort of an advance notice that you'll be putting out a call for measures, and I just wonder if that might be an option here --

DR. WINKLER: Yes.

DR. SCHWALENSTOCKER: -- thinking about these might be harder measures to find.

DR. WINKLER: Well, yes actually it's become fairly recently, but part of the process to issue an intent kind of call, sort of a flagging, yoohoo out there we're doing this and ask them to just send in the list so we have a sense of what we're working with, you know, to give us some sort of forewarning.

We're only getting a fraction of the ones that actually end up being submitted. I mean we ended up with 14 on the intent for the main call and we got 50 measures submitted.

So, you know, but you're right.

To the degree that we can, you know, broadcast this information and we're due to issue that intent in December, it's got to be. So we'll be doing that.

DR. SCHWALENSTOCKER: Yes, I'm just thinking it may not be so much that you'll get that initial list, but you get --

DR. WINKLER: But the information is out.

DR. SCHWALENSTOCKER: -- people thinking ahead of time and a chance for us to use, you know, whatever vehicles we have to disseminate information, repeated messages. So it might be a way to go.

DR. WINKLER: Yes, no that's great. Thanks Ellen. Absolutely.

DR. CLARKE: Is risk adjustment part of the submission if appropriate?

DR. WINKLER: Yes.

CO-CHAIR HOMER: Yes.

DR. WINKLER: Absolutely. Kathy's had experience submitting a measure and it's

very, very detailed over all the measure evaluation. What we'll do is bring you to project sort of an example of a measure that's been submitted.

The way we've got it set up is with the electronic submission now it merges into the evaluation form, and we'll bring you an example of the evaluation form that you're going to see and it sort of sidebars where you can, you know, evaluate it.

But there's the criteria and then what the measure -- the information submitted by the measure developer right underneath it to address it. And you'll decide, does this meet that criteria or not, but the two are paired.

And it's very detailed, I mean those, each of those run what 10 page or so. I mean the subcriteria under each of the four main criteria are fairly extensive.

DR. JENKINS: The only other framework that I could think of that might be

helpful to make, I don't know, but to make the link between these population based measures and the actionable by the health care system measures is I think something that IHI has developed. I saw Maureen.

CO-CHAIR HOMER: The triple aim framework?

DR. JENKINS: I'm thinking, you tell me because I saw it awhile ago, it's just always been in my mind, about moving the big dots and that one of the ways to move the big dots is to have everyone know what the big dots are and then basically elaborate precisely how their actions will contribute to moving the big dots.

In this case obviously to what extent do the population health measures be able to be moved through action through the health care system is the obvious link, but for the community or other groups that might also want to move those population health ones that could be helpful. It's not ringing a

bell?

CO-CHAIR HOMER: No, it absolutely is ringing a bell.

DR. JENKINS: It was a whole talk on how do you move the big dots and strategies to do that, it's really about alignment.

CO-CHAIR HOMER: Yes, it's about alignment. So again it's just -- I mean the idea in part is how to move quality improvement away from doing these small isolated cool little projects to having a strategic aim and aligning your projects with a strategic aim.

So the way that the thinking has evolved has really turned into that driver diagram, I mean that driver diagram is meant to reflect and that's what the IHI and other groups are using.

It's sort of a logic model, but the idea is those are each the drivers that if you -- the ones to the right are basically the small dots, the small activities that would

then lead to the larger dots.

So I do think that that would be a useful way for us to -- could be a way to actually graphically present either in the call for proposals or help us organize when we get these things in.

If this is the outcome we want to achieve, which is perhaps kids being healthy and ready to work and live and things like that, and what would be the different components that would lead us to getting there, which could include the community outcomes and the clinical -- I mean I'm just thinking off the top of my head.

So I think that's the connection between the big dot, the driver diagram and where we are here. It's good. I can send you the slides with the big dots.

CO-CHAIR WEISS: The one thing that we haven't brought into the equation here though is the earlier point that you made, Charlie, about the education performance of

the children. Is this something that we would like to tell Reva or Helen about what we'd like to see either in the initial introductory remarks about the call for measures or?

CO-CHAIR HOMER: Well I think that would be included in those broader measures of community outcomes, I think.

CO-CHAIR WEISS: So maybe as a --

CO-CHAIR HOMER: As an example.

CO-CHAIR WEISS: -- parenthetical example or something of that nature?

DR. CLARKE: I'm just wondering is part of our task also taking the next step in terms of how a particular measure can be used to evaluate health care performance?

DR. WINKLER: Typically NQF does not get into that very deeply. In terms of the implications on potential use as it influences how you evaluate the measure, we can't draw hardline on it because a lot of the evaluation is around feasability and usability.

So you can't totally disassociate, but we have no control over how it actually is used. Recommendations that go along with it, sure. Leverage, not a lot necessarily. But if you think they're important aspects, and I think the one that could be particularly useful is reinforcing the level of analysis for which the measure was developed and intended to be used.

Again, we have no control over what goes on out there, but making that clear that you're evaluating it for use at, it's only going to be used -- this measure is only good at the health plan level or for sufficient populations of a large enough size, blah, blah, blah and isn't intended for smaller levels of -- lower levels of analysis or smaller populations, you know.

I think to state that is very reasonable because you've done the evaluation of its technical merits and a lot of this is the technical aspect of sample size and all of

that.

So to that degree I think it's reasonable to make those comments, but there is just, you know, these measures get used in a whole wide variety of fashions so we can't -- and I think that's part of the -- something to keep in mind is NQF endorsed measures are used in a variety of ways.

But typically on the high level of accountability whether it's publishing it on a website or in a payment incentive program or in a, you know, who's in and who's out of a network situation. So significant levels.

So you want to keep that, that that's what we're doing when you're evaluating the measures. And so that's why we do want them to meet the criteria to a significantly good degree. The stakes are high, we know that.

CO-CHAIR HOMER: Tom?

DR. MCINERNY: I'm wearing a couple of other hats for the AAP. One, you

know, we're finishing up our mental health project for primary care, we have a mental health taskforce, we're going to publish a toolkit sometime in probably mid-2010 I hope, it's closing in on being finalized.

And the goal is to try to get primary care pediatricians to be more comfortable with, to be more knowledgeable about identifying and treating mild to moderate mental health problems in children because there just aren't enough mental health specialists to go around and we all know that a small percentage of kids get mental health care who need it.

And I don't know when we're doing the call for measures if we could specifically kind of look for some outcome measures for how, particularly one of the things we're looking for is for primary care pediatricians to collaborate with mental health providers, and are there some measures that look at that that lead to better outcomes.

I don't know, but that's one thing that I think is important, and again need to dovetail that with the mental health group that NQF has. Because it's, I mean clearly it's the new morbidity and, you know, we know that it's close to 20 percent of kids have some kind of mental health problem and that's far bigger than most anything else you can think of.

And then the other area that's --

CO-CHAIR HOMER: So let me maybe respond to that because I'm sure I'll forget. So one thought is to make sure that when we put out the call that we specify, if we use something like the acute chronic preventive frameworks something like that in there is that we include mental health.

So I think we need to explicitly include mental health in that and flag it. I personally think that something like -- and this relates to the care coordination discussion we had before that collaborating

between primary care and mental health is a beautiful thing, but it's a process and the outcome is the outcome.

So, you know, whether it's the child mental health status or functional status or family functioning or something along those lines would be my inclination.

DR. JENKINS: or cost.

CO-CHAIR HOMER: Or cost, yes. But we heard that cost was only quasi within our jurisdiction here. So that was your other half of your question, I hope I didn't derail you.

DR. MCINERNY: Yes, the other is the other MH and that is the medical home and that's clearly not a big resurgent -- big all of the sudden interest at least and what's bothersome to me is the pediatrician is at -- almost everything you hear about these days is with family physicians and internists and pediatricians who invented the medical home are being left out left and right.

There's not very much going on in that and actually we're putting together an EQIP module on the medical -- on helping pediatricians to, you know, make their practice into a good medical home. And again, you know, what measures do we have, outcome measures that indicate that, you know, if you've done all this work, how do you know it's really working?

CO-CHAIR HOMER: Again I care a lot about this topic, I wrote the background paper for the AHRQ committee on basically the medical home, it was framed in the legislation as the most integrated health care setting.

But again, that's, I mean the existing measures of medical home as you know are largely structural never mind process and there are some patient experience, reports of those processes.

But I guess I would say what we would want in this one, again if we were to even mention it in the call it would be

something that would capture the desired outcomes of a medical home, but they should be captured by the other things that we're talking about, I would think satisfaction, cost --

CO-CHAIR WEISS: Care coordination.

CO-CHAIR HOMER: -- care coordination outcomes. So maybe care -- but again outcomes.

DR. MCINERNY: Apparently ***4:14:49.

CO-CHAIR HOMER: Yes.

DR. WINKLER: However, would it really be particularly bad to include as some of the desirable things or desirable outcomes would be measures of the effectiveness of care coordination or the medical home, I mean just to be explicit?

CO-CHAIR HOMER: No, I think you should mention it. I think it's such an important trend right now and something, yes,

I think it's a good thing.

DR. DOCHERTY: And speaking along the lines of our areas or the hats we're wearing that we want to make sure, and I think it's covered in this conceptual model, but you know, when I think about hospitalized children and I know that that's -- if we're talking about numbers of affected, this is a lower amount.

But when I think about children that are left in hospitals today, those are very sick of the sickest. And more than -- of children that die, more than 50 percent of them, unlike adults, die in the hospital.

And so palliative care services is one thing that children's hospitals struggle with. And so, I was keeping my eye out for it today, you know, and I think that the way we measure whether or not children got good quality of life care/palliative care is sort of the through the parent satisfaction, long term, you know, trying to understand, you

know, while their child was in the hospital or died in the hospital did they get the kind of care that the parent felt.

So I just wanted to make sure that if when we put out the call that we had sort of tweaked the eyes of those people that can measure that kind of thing in parent satisfaction.

DR. WINKLER: NQF has actually endorsed a survey a families about end of life care. The question is, does it capture kids? It does, okay. It's just something -- I'm not sure it ended up on our list. Now that I think about it I don't remember if I saw it.

Yes, and only because I think the thinking tends to be more at the other end of life. But if kids are involved, it definitely should be on the list. We'll need to amend that.

CO-CHAIR HOMER: Again, just following up on Marina's question to me earlier about for example the school

performance. So, I guess to me that kind of measure falls into two areas, one are these broad community health measures, which is what we want.

But there will be people submitting measures I think on, for example, asthma. And I would want the people who are submitting the asthma related measures or other conditions to think broadly in that about outcomes that may occur outside the immediate health care context, which would -- so I think we'd want to pick that up in two different places.

We've done excellent work as a committee today. I want to thank the staff for excellent preparation, I think in leading us to rich discussion. I want to also thank NQF for selecting a great committee, because really this was an extraordinarily rich conversation.

And I think I speak for Marina in saying how much we're looking forward to

working with you over the next -- how long is our duration by the way? Do we have a timeline?

DR. WINKLER: Yes, you do have a timeline. As I mention, we'll be doing a call for measures over the winter and you'll meet again in April to formulate your recommendations and that will start the rest of the consensus process.

So we'll be friends fairly closely through at least the first half of 2010 and the project will end, I believe it's October in final endorsement. And so we'll keep in touch with you on that. But so the active work will be in the next, you know, six to nine months.

CO-CHAIR HOMER: That will be great. So looking forward to working closely with all of you. Allan?

DR. LIEBERTHAL: Before we finish, for those of you --

DR. WINKLER: Use your microhphone.

DR. LIEBERTHAL: This actually is not on the topic that needs to be recorded. For those of you who came in today may not be aware the restaurant in the hotel is not open for dinner. So I wanted to find out if people wanted to go find a restaurant.

DR. WINKLER: And in fact what we did, because a couple of you asked, is Ashley has out front a list of restaurants in the area. This actually in the area around Dupont Circle there are an awful lot of really interesting small ethnic restaurants so there's a lot.

But the list is rather extensive, they've starred a couple they think are grand and we very much encourage you to explore and even though it's rainy out there, you're pretty close to a couple of really nice ones. So the list is out on the front table that Ashley has for you.

I think we're starting at 9:00 tomorrow morning. There will, I think coffee

starts at 8:30, yes. And so our morning, we may finish more around noon-ish. We'll have to kind of see, you guys tend to be a bit efficient.

But we've talked about what the plan is for tomorrow, we're going to talk a little bit about, you know, how to -- not only what does the call for measures say, but who do we send it to.

And then we'll talk a little bit more about the measure evaluation process so that you'll have an idea of what's to be expected the next time we actually meet in person, though I do anticipate we'll have a conference call or two before that to keep you up to date on what's going on.

And once we have a better handle on the response to the call for measures, see how good we were, we'll know what the work plan is a little bit more detailed.

So any questions for anybody? We're certainly going to be here, we're

actually not planning on picking up and leaving right away, we've got work to do for you. So if there's any questions or issues, feel free.

DR. BURSTIN: I'll just add that we also will look towards you to tell us where there are some good measures. So we don't often get just what comes in over the transom. Actually, a good number of those measures and the larger outcome, the adult outcomes committee came because of lots of sort of shoe leather work on the part of the steering committee and us.

So let us know if you know there's some good pockets of measures out there. For example, going back to your point earlier, measure developers who wouldn't otherwise think to submit to NQF, please let us know. We're happy to sort of the queue them to get them in.

(Whereupon, the foregoing matter went off the record at 4:21 p.m.)

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