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

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1	P-R-O-C-E-E-D-I-N-G-S
2	9:58 a.m.
3	CO-CHAIR WEISS: Good morning
4	everybody, if we could begin. Maybe everybody
5	take their seats and let's get started. I'm
6	Marina Weiss and I'm co-chairing with Charlie
7	Homer who has a phone call that he has to do
8	right now, but he'll be with us shortly.
9	And if you don't mind, I'd like to
10	hold introductions and descriptions of how
11	you, the path by which you got here until
12	Charlie arrives so that he too can hear that.
13	But I think we have some I'm not sure
14	exactly what Reva has in mind for us today,
15	but I think she's going to lay out some
16	general perimeters for the meeting. And so
17	let me turn it over to Reva Winkler.
18	OPERATOR: Ms. Marinelarena?
19	CO-CHAIR WEISS: Yes.
20	OPERATOR: Hi, this is the
1	OPERATOR: HI, CHIS IS CHE
21	operator handling your call today, are you

1 conference?

2 CO-CHAIR WEISS: Yes, we are. 3 OPERATOR: Okay. I'm going to 4 transfer you now, you'll hear music for just 5 a moment and when that disappears you can 6 begin.

7 CO-CHAIR WEISS: Thank you so 8 much.

9 DR. WINKLER: Hello, is someone on 10 the phone? Anybody there? Okay. Hi 11 everybody, I'm Reva Winkler, I'm one of the 12 NQF staff members, part of the project team 13 that's overseeing this project that you so 14 graciously agreed to part of with us.

What we're going to do in these 15 two days is several things, we want to get you 16 up to speed on what NQF is doing these days, 17 we're a growing organization, some of you are 18 familiar with our work, you've worked with us 19 20 in the past, some of you less so and we'd like to get everybody sort of in the same place and 21 22 understanding what NQF does and particularly

1	what our work in this particular project is.
2	As well as we have a couple of
3	tasks for this committee to do to help us set
4	the directions and the subsequent activities
5	for this project. And we are focused around
б	outcomes. This is this effort is part of
7	a larger project that is funded by the
8	Department of Health and Human Services around
9	patient outcomes.
10	We actually have it broken up into
11	several pieces, one the largest piece of it
12	is focused in on adult outcomes around sort of
13	the top 20 Medicare conditions, if you will,
14	certainly a big focus of the Agency. But in
15	addition to that, we also have and they
16	have their own steering committee and
17	technical advisors and all of that.
18	But in addition to look at some
19	other areas, we also have a steering committee
20	for mental health conditions, primarily
21	Alzheimer's disease, depression and those sort
22	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.

4 And so while you're part of a 5 bigger project, you are essentially the decision making body. And we'll talk about 6 7 the role of the steering committee a little bit more later in the morning, but our focus 8 9 will be on looking outcomes for child health. So what I'd like to do, and we'll 10 break whenever Charlie arrives so we can do 11 the introductions, is just kind of start out 12 13 with sort of an orientation to NQF and some of the things that we think you should be aware 14 of to make it easier for you to be a member of 15 the steering committee and understand what 16 we're asking of you and to play that role. 17 So this is what we're going to be 18 doing today. The goals of this two day 19 meeting is to do this orientation and we are 20 21 going to discuss the scope of this project,

22 what do we mean by child health outcomes.

1 This is going to be one of the, I 2 hope, one of the more interesting discussions that we have this afternoon and tomorrow. 3 And 4 then we'll just talk about NOF standard 5 measure evaluation process rather briefly. Okay, Melissa the next one. 6 7 So just I'm sure all of you are aware of what NQF is, but just as a very, very 8 9 brief summary we are a non-profit 10 organization, we are a membership organization, we have over 400 members now 11 representing a wide variety of stakeholders. 12 13 We are specifically a multistakeholder organization around issues of 14 quality measurement in health care. Our 15 structure is a typical non-profit structure, 16 but there are a couple of interesting aspects 17 of it. 18 The Board of Directors oversees 19 all of our work, but our Board of Directors 20 21 contains representatives from government agencies. We do have a subcommittee of the 22

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

4 And then we also are working very 5 closely with the National Priorities Partnership and we'll talk a little bit more 6 7 about that. And then our leadership network is the chairs and vice chairs of each of our 8 9 member councils to provide input and advice 10 through those specific stakeholder groups. 11 So, next.

12 This is a screen shot of NQFs new 13 website, and I would encourage all of you to go there. And you can see that you, over on 14 the right-hand side, you can enroll as a 15 member, anybody can, there's no qualifications 16 besides willingness to fill out the form, to 17 give yourself a log-in a password and access 18 to it. 19

20 Because you can create your own 21 dashboard so that when you log in, all the 22 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.

4 So this particular project is 5 phase III of the outcomes project, child 6 health, so you might want to put that on your 7 dashboard as well as whatever else interests 8 you that we may be doing.

9 And I encourage you to kind of 10 search through that website because there's just an awful lot of stuff in there. NOF has 11 an awful lot of activities, we're going to 12 13 touch on a few of them in the next few minutes, but it's fairly wide ranging and you 14 might be interested in some of the other 15 aspects of NOFs activities. And so I 16 encourage you to register and check in with 17 18 us. 19 But it will be a way to follow the 20 process that we're going to take measures through for child health. Next one. 21

22 Just -- we've given you a copy of

the slides, every organization has a mission 1 2 and vision statement, this one is ours. And essentially we have a three-pronged mission. 3 4 And one is improving the quality 5 by setting our national priorities and goals, and we'll talk more about the National 6 7 Priorities Partnership as an activity for that. 8 9 The second bullet is really the 10 action that we're working on, and that's endorsing national consensus standards for 11 measuring and publically reporting on 12 13 performance within the health care system. So this is the work we are doing. 14 And then, we also have activities 15 around promoting the goals through education 16 17 and outreach programs. So these are the sort of big sort of buckets of activities that NQF 18 pursues and you're working primarily in the 19 20 second one. Next one. 21 Again, just to show you our, 22 generally our strategic goals is NQF

essentially endorses -- is the principal body 1 2 that endorses national health care performance measures, quality indicators or quality of 3 4 care standards. So that's -- those are our 5 strategic goals, that's sort of our role in 6 7 this, the quality enterprise in this landscape. Through measurement we are 8 9 striving to improve the overall health care 10 system and by the contributions of endorsing measures standardizing measurement on a 11 national basis, we are carrying out our 12

13 various missions.

NQF is now 10 years old. 14 We celebrated our 10th anniversary this year and 15 I've been around for nine years of it. Though 16 it's a rapidly growing organization, Marina I 17 think you've been around for 10 year of it, 18 from the very beginning. No, she's been there 19 even before me, from even before I think when 20 21 it was a twinkle in somebody's eye. 22 NOF has done a lot of work in that

10 years. Over that period, the focus has 1 been on evaluating and endorsing measures as 2 national voluntary consensus standards. 3 There 4 is a growing and continually urgent need for 5 more measures. 6 It's also an evolutionary process, 7 it's not just essentially more measures as a volume, but better measures as time goes on as 8 9 everyone embraces measurement and the 10 information we gain from it can be used to 11 drive quality improvement, better measures, more robust measures, different kinds of 12

13 measures than we initially started out with 14 are needed.

So this is a constantly evolving 15 process, it's not a matter of numbers. 16 So currently at this point there are several 17 drivers that are driving the work we do. 18 Measurement -- measures are needed for 19 20 accountability programs of various kinds whether they're public reporting, whether 21 22 they're pay for performance, whether they are, you know, any other kind of incentivization or
 accountability program.

Certainly within the measures that 3 4 we've looked at over the years, there are gaps that need to be filled. Certainly many 5 stakeholders identify, you know, it's great 6 7 that you've got these measures, but we need measures that do this or provide this kind of 8 9 information and there are large gaps. 10 We've been working on filling the gap for measures suitable at the individual 11 physician level, that's essentially the work 12 13 I've been doing for the last three or four years and we now have a significant number of 14 measures across a large variety of conditions 15 that can be used at the individual level. 16 Disparity sensitive measures. 17 Issues around disparities are a continual 18 concern and how do you use measurement to help 19 20 us understand that. There are certainly 21 measurement challenges around how do you -getting the appropriate data to allow you to 22

1 stratify results.

2	But certainly keeping disparities
3	front and center as an issue and a concern
4	around measurement is definitely one of our
5	priorities. Patient experience in many
б	settings, we do have we have endorsed
7	multiple tools for assessing patient
8	experience with care, some for children, some
9	for adults, some for hospitals, some for
10	outpatient.
11	There are probably areas that
12	still need to be addressed, but it is an
13	important area to get the patient perspective.
14	And then crosscutting areas that aren't so
15	much disease or condition specific, but would
16	apply to all patients either and particularly
17	across settings.
18	So there are still a lot of areas
19	of where measures are needed. And that's
20	going to be one of the issues we're going to
21	ask you to help us deal with, particularly as
22	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 4 5 and what we need? We need some sort of a structure to be able to organize it so that we 6 7 can either identify existing measures to know that they'll fill one of these slots within 8 9 our organizational structure or our framework, 10 or if they have not been developed, how do we identify that specific need for measure 11 12 development.

13 So these are the primary goals for our project around child health. A couple of 14 key issues as we've reached our 10th year, 15 our portfolio of measures contains about 550 16 measures and I just completed a project that 17 allowed another 70, so we'll top 600 18 relatively soon. 19 And the question is, you know, is 20 21 it too many, is it too few, but more 22 importantly are they the right measures.

1 And I think we're seeing, as we're 2 going through our measures maintenance process, that some measures that seem 3 4 perfectly fine five years ago really don't 5 have a great deal of utility now, they've been 6 superceded by better measures or they're 7 topped out, they aren't being used, they aren't found to be particularly great drivers 8 9 of quality improvement. 10 So, this portfolio needs to undergo constant review and modification 11 revision updating. So it is a work, always a 12 13 work in evolution, it's not a static thing. 14 Another thing that's changed over the 10 years that NQF has been endorsing 15 measures is data sources, you know, there are 16 some traditional data sources, but there are 17 new data sources. We're getting perhaps 18 closer to having sort of the ultimate data 19 20 source through electronic health records. 21 That certainly is not without its 22 challenges, but there seems to be an

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

5 So all of these things overlie all 6 of the work that we do. So we need to keep 7 those in the mack of our minds as 8 considerations as we're looking at how do we 9 measure outcomes for children.

10 Okay. Again as I mentioned 10 11 years of experience, we are evolving. We get 12 feedback from all of the various stakeholder 13 members in terms of what their needs are out 14 there for measures. They want to use them, 15 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

1 kinds of measures.

2	Shifting towards composite
3	measures, another strong message we're
4	hearing, how do we package information in ways
5	that make it easier for all sorts of
6	stakeholders, but particularly consumers and
7	purchasers to really understand the value of
8	the care that they may be getting or paying
9	for.
10	Among the composites are concepts
11	around like the perfect care measure, did this
12	did a single patient get all five elements
13	of appropriate diabetes care, you know, how
14	many of your patients received all of them.
15	Way to take measures that are all
16	looking very good on performance across the
17	board, but ask the question somewhat
18	differently, raise the bar a little higher and
19	suddenly there's room to improve. So pushing
20	these measures farther is certainly the
21	message we're getting.
22	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 4 5 measure specifications, when we're talking with the measure developers, when we know it's 6 7 a condition that disparities play a role, we need to really dive in and ask how can we use 8 9 this measure to help us understand more about 10 disparities and potentially drive change around those disparities. 11

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.

17 The definition of who's included, 18 the diabetic by age, by whatever coding you 19 use, shouldn't vary, even just the littlest 20 bit from one measure to the next. Either 21 you're measuring the same group or you're not. 22 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 6 7 a harmonious group, we really need to try and foster alignment along those measures to the 8 9 degree possible. Certainly, age inclusions 10 are an important one, but some of the definitional issues of who's included in a 11 denominator for any particular condition, 12 13 who's excluded, those sorts of things; real important aspect of harmonization. 14

We're hearing from the people who 15 want to use the measures out in the field that 16 without that harmonization, it's just too hard 17 for them to implement a measure that's, you 18 know, this one's this way and the next one's 19 20 slightly different. So that's going to be a 21 very important overlay to what we're doing. 22 And we certainly want to see more

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

5 To that end, outcome measures are 6 a critical aspect. That's why you're here. 7 Finally, people are willing to, you know, 8 let's talk outcomes.

9 For the longest time, process 10 measures have been the focus, the comfort zone, but the need to really start talking 11 about where it counts, what patients care 12 13 about what, purchasers care about and ultimately all providers and professionals 14 should care about or what ultimately happens 15 to the patient, what are the outcomes. 16 So that's why we're here. 17

18 Other issues that we want to try 19 and tackle are appropriateness measures, you 20 know, having a surgery go well and without any 21 complications are great, but did you need it 22 in the first place. Those questions need to

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

3 Cost and research measures coupled with quality measures, definitely. Big, big 4 5 interest in that, particularly in the consumer purchaser plan, you know, folks. And I think 6 7 it's something everyone needs to be aware of and interested in because health care costs 8 9 are just really quite high. So those are the kinds of issues 10 around quality measurement that NOF is trying 11 to focus on. We want to keep these in mind as 12 13 we do the work of this project because we do want -- one of the roles of the staff is to 14 try and keep all of you aware of all the other 15

16 NQF activities that are ongoing, to keep 17 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.

22

Just a brief expanse in

1 disparities. We've had numerous conversations and efforts around disparities and so several 2 conclusions that I want you to be aware of as 3 4 we go forward looking at potential measures, 5 certainly there are a lot of measures pertaining to child health where disparities 6 7 are a significant concern. And so sort of the initials are 8 9 principles around looking at disparities is 10 that assessment of the potential ways you may 11 characterize patients by race, ethnicity, primary language, SES status should be routine 12 13 in performance measurement. And again I think for every -- any 14 measure that we see, we ask the question have 15 you considered it and if not, why not and how 16 can you -- how could you consider it in 17 implementing this measure. 18 Certainly there are challenges in 19 20 collecting the data, and so exploring the data collection methods for gathering the 21 22 information you need to do that.

1	And then particularly identifying
2	those measures that are particularly disparity
3	sensitive that we know there are issues around
4	disparities and really try and drive to those
5	measures being stratified being able to be
6	stratified by these various perimeters such
7	that we can get better information on
8	disparities and monitor and trend and
9	understand performance and changes over time.
10	Another phrase I mentioned in a
11	previous slide was episodes of care. And
12	rather than looking at real point in time
13	issues where measures are easier to do and
14	have been more common in the past, we want to
15	look at things from a patient perspective and
16	that's an episode.
17	I mean, it didn't just happen in a
18	single doctor's visit from the patient's
19	perspective, it happened over a period of time
20	and for those with chronic conditions, over a
21	long period of time.
22	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.

5 And this is an example of a framework around acute MI, it also happens to 6 7 encompass coronary artery disease when you look at the first bubble. These are our 8 9 bubble diagrams, I've actually been in the 10 audience at any number of meetings and people have been using our bubble diagrams to sort of 11 demonstrate this concept of an episode of 12 13 care.

So this is a concept that's 14 growing and finding its way out into the 15 And we plan on using this in some of 16 world. the outcomes work around certain conditions. 17 I'm not sure exactly if we could use it around 18 child health, we'll have to think about it. 19 20 But certainly looking at the 21 various phases that a patient experiences under certain conditions, and these help us 22

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.

7 So this is a framework that we're using a lot and at this point it isn't clear 8 9 to me that it is something we will use in 10 child health, but if you guys can help me figure out a way to do that, I'd like that. 11 12 Right now it's not -- I can't 13 quite figure it out, but with all the good minds around the table perhaps we'll be able 14 So I wanted to make you aware that this 15 to. is something, a tool that we are trying to use 16 to the greatest degree possible. 17 Next one. I'm going to take a deep breath. 18 Okay. I also mentioned the need for a 19 20 national priorities and goals, certainly as one of NOFs missions. This is a focus on 21 22 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 3 4 all sorts of people. The quality measurement 5 enterprise is a large one, there are lots of organizations working in this space, and if we 6 7 all work together we're likely to make much more progress than if everybody's doing their 8 9 own thing. 10 Certainly individual efforts have been, you know, wonderful and successful but 11 if we can just pull those all together I think 12 13 we can get some exponential progress and accelerate where we're trying to go. 14 15 So about two years ago NQF was involved in working with a group of partners, 16 32 organizations, very -- you can probably 17 name them, but across the stakeholder 18 landscape organizations that are very much 19 20 invested in quality measurement and improving 21 health care quality. 22 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.

6 So this is an activity that NQF is 7 very much involved in, working with the 8 partners to align all of these efforts. Next 9 one.

The work of the National 10 11 Priorities Partners over the last two years since they launched their activities was to 12 13 try and identify priority areas and goals to focus on so that with everyone looking towards 14 the same priorities, same goals to build on 15 and have sort of an accelerated additive 16 effort. 17

18 Their analysis of various types of 19 measurement, the potential areas and 20 priorities they were able to identify the high 21 impact areas and those are, they came up with 22 six priorities, all right.

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1	For those of you who have been
2	working with the Priorities Partnership, I'm
3	sure these are very familiar to you, for those
4	who are not, it's important this is an
5	important work that NQF is doing in trying to
б	align a lot of the work with the partnership.
7	The first priority area is to
8	is around care coordination, cost providers
9	settings and levels of care. The particular
10	current goals are around medication
11	reconciliation, preventable hospital re-
12	admissions and preventable emergency room
13	visits.
14	So that's you'll see in a great
15	many of the work a lot of the work that NQF
16	does regardless of the project, these are the
17	kinds of measures that are very important ones
18	and we do flag then as being aligned with the
19	National Priorities Partnership's priorities
20	or one of the goals. You'll also see that in
21	our evaluation form when you do measure
22	evaluation.

1 The second main goal is in 2 population health, improving preventive services, healthy lifestyle behavior with 3 ultimately -- with an ultimate goal of 4 5 creating a population or community health index to better understand what's going on, on 6 7 a bigger picture. And I'd like to introduce one of 8 9 our newest colleagues to NQF, Dr. Bonnie Zell, Bonnie wave to the folks. She's leading up 10 our efforts around population health and 11 she'll be talking with you later this 12 afternoon about how do we think about 13 population health and children's health. 14 15 How do those two come together, how can we find perhaps meet some of the needs 16 of the population goal or priority at the same 17 time as we're looking at child health 18 So we want to keep that in mind. 19 outcomes. 20 Another of the priorities is 21 around patient safety. Patient safety, huge, huge issue. We have a lot of activities 22

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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

8 beginning of its existence, we've had projects 9 around and endorsed the serious reportable 10 events, and it's a growing list.

of patient, you know that almost from the

7

We've also endorsed the safe 11 practices and they've been revised and updated 12 13 several times. So these are actually NQFs inhouse works and has been sort of the backbones 14 of NQF as a growing organization. So patient 15 safety continues to be a very significant goal 16 in the work that we do. I must have skipped 17 something, there we go. 18

19 The fourth one is patient and 20 family engagement. A very important aspect of 21 care delivery, difficult to measure, but 22 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.

7 Certainly we need more information around informed decision making, more patient 8 9 experience with care and more around patient 10 self management. So those issues are 11 certainly, and measures around those issues 12 are certainly things that would be very 13 important and very desirable for us if they should come across this project. 14 The fifth one is end of life care, 15 palliative and end of life care, compassionate 16 care, relief of symptoms, meeting patient 17 needs and access to palliative care and 18 hospice services. Certainly an important 19 20 aspect of care to be addressed.

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

appropriate care. So it's an appropriateness 1 2 with some emphasis on overuse. Certainly it's well acknowledge that there is overuse of a 3 4 lot of different aspects of care. Next one. 5 And the potential areas that the partnership is looking at, are those that I've 6 7 listed in appropriate medication use, unnecessary labs, unnecessary diagnostic 8 9 procedures, unnecessary maternity care, 10 interventions, unnecessary consultations, U.S. Preventive Services Taskforce de-11 recommendations like don't do it, that are 12 13 still unfortunately being done, as well as preventable hospitalizations and ED visits and 14 inappropriate end of life care. 15 So these are areas that the 16 partnership is tackling. And if we see 17 measures that come across this project that 18 support that priority and goal, we will want 19 to note them and consider them within these 20 21 priorities. Next one. Just to -- the National Priorities 22

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Partnership is something NQF is active in and 1 we support through our convening function, but 2 it isn't, you know, a wholly owned subsidiary 3 of NOF. So it is sort of a separate entity 4 5 that we work with very, very closely. They have their own website I'll 6 7 point you to, a lot of things going on there, a lot of detail of the goals and priorities 8 9 that I just briefly summarized is in there, a lot of information. 10 So feel free, and I encourage you 11 to go check that website out to -- so you have 12 13 a better understanding of all the stuff going on with the National Priorities Partnership as 14 well as a list of the organizations that are 15 involved. 16 So we've got priority 17 partnerships, we've got episodes of care, so 18 let's slam it all together and what do we get? 19 20 This is the bubble diagram plus NPP, courtesy of my boss, Dr. Helen Burstin who we'll 21 introduce ourselves a little more throughly 22

1 later.

2	But this is how we're trying to
3	keep in mind all these different aspects of
4	the work that NQF does. And so these are the
5	kinds of diagrams that help us organize our
б	thinking and organize our work so that we
7	don't lose site of important aspects.
8	So one of the things that we're
9	going to be asking you to help us think
10	through around child health outcomes is
11	something similar, what are all of the
12	dimensions, what are all of the domains, what
13	are all the aspects of care around for
14	child health that we need outcome measures for
15	to both help us identify those outcome
16	measures if they exist, or how do we say we
17	need a measure that looks like this.
18	So that's going to be really the
19	crux of the project we're asking you to help
20	us with. Further on in terms of NQF
21	activities, we're doing an awful lot of work
22	around IT. Some of the led by Dr. Floyd

Eisenberg, we're working with several projects 1 to help the -- accelerate efforts around the 2 EHR development, what health information is 3 4 needed to support performance measurement. 5 There has been a lot of money from 6 the recovery and reinvestment act for 7 stimulating use of electronic health records. We need those records to be developed in a way 8 9 that will become very useful for performance 10 measures. 11 And so we are certainly involved with all of the variety of efforts both within 12 13 the federal government and in the private sector too, to come to sort of a common place 14 so that when providers adopt those EHRs they 15 provide the functionality and they can do all 16 the things we hope they'll be able to do 17 because it's not a simple thing. 18 19 And go to the next one. Because 20 data is tough. Right now we have a very complex world, a lot of data, a lot of 21 potential data streams, lots of need for data, 22

1 lots of need of data analysis.

2	And so trying to put this into a
3	package that provides the information out is
4	a very difficult one but it's something we've
5	got ongoing activities around.
6	And some of the more interesting
7	work that we're doing is around the quality
8	data set. This is a set of data elements that
9	we've actually created from the measures that
10	NQF has endorsed to help, you know, how do you
11	break it down into little pieces into data
12	elements so that that data could be captured
13	in electronic platform.
14	Also looking at how is this
15	embedded in a normal workflow so that
16	measurement isn't is part and parcel of
17	care delivery and not something that's done
18	after the fact or as an added burden.
19	These quality the quality data
20	set with these defined data elements in a
21	standardized fashion, the next step is a
22	measure authoring tool so that someone who

wants to create a measure about something, you 1 know, you don't redefine patients with 2 diabetes, there is the definition, go to the 3 QDS, put that up, fine. Now what do you want 4 5 to measure about them? 6 There's a good chance we may have 7 already had some of those data elements already defined. Trying to maintain 8 9 standardization sort of an up-front 10 harmonization, if you will. 11 So these are some of the ongoing activities that probably won't touch us very 12 13 directly, but the work we do will impact because the measures we evaluate and move on 14 will get fed into the QDS. Any other comments 15 you want to make about that Helen? 16 Okay. So I'm okay, where's 17 Charlie? Just because we're running a little 18 ahead of schedule, we're supposed to be 19 introducing ourselves and I sort of hate 20 continuing to talk to you without it. Please 21 22 use all of your microphones, we are recording

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

5 DR. JENKINS: I have a question. Just in related to what you say, can you give 6 7 us a little bit more understanding of in this process or perhaps in the general NQF process 8 9 about the high stakes accountability pay for 10 performance metrics versus what you also alluded to earlier is the more quality 11 improvement perhaps not at that level metrics 12 13 and just give us the overall on that. DR. BURSTIN: Of course. 14 So overall, I'm Helen Burstin by the way, we'll 15 do our intros shortly I guess. The overall 16 goal of what NQF does is really to endorse 17 measures that are appropriate for public 18 reporting and quality improvement. 19 20 There's expectation for both. The 21 public reporting really is the sort of 22 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.

7 So we mainly focus on a higher 8 level, those higher level ones perhaps as you 9 refer to them, and one of the reasons this is 10 especially important is NQF endorsement is 11 required when the federal government chooses 12 to seek to use measures for any of their 13 public reporting programs.

There are options that they can go 14 around it at times, but in general that's been 15 What's a little unique about this 16 the case. situation is that much of that work has been 17 done in the Medicare environment, very little 18 around children and Medicaid, in particular, 19 20 although health plans have certainly focused on some of this. 21

22

So I think because of that, and

certainly Reva knows the work around CHIPRA 1 2 quite well, there's a lot emerging I think about the way quality measures might get used. 3 I don't know if you want to mention anything 4 5 about sort of the policy landscape or what's happening with CHIPRA as an important piece of 6 7 background as we think about the role of these 8 measures.

9 CO-CHAIR WEISS: Yes. For many of 10 you who follow pediatric issues, I'm sure are well aware that with enactment of the re-11 authorization Bill that brings the CHIP 12 13 program. Children's Health Insurance Program forward to the year 2013 that there was added 14 to that Bill a very robust section, I think, 15 that moves both the CHIP program and the 16 Medicaid program so far as it's involved in 17 covering children toward more aggressive 18 posture with respect to the development and 19 20 use of quality measures.

21 And so that, the implementation of 22 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 8 9 measures that are supposed to be out there. 10 And as I say, they are a core set, but there 11 is every expectation on the part of members of Congress who were involved in putting together 12 13 the quality section of the bill and also the Secretary and folks over at HHS that this is 14 15 just step one, that there are many other steps 16 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 1 to be a part of it. 2 DR. JENKINS: Just for 3 clarification, do you all use any standard 4 5 terminology to distinguish like the lower level measures from the higher ones? 6 7 Because I know the American College of Cardiology uses performance 8 9 measures as opposed to quality metrics, just 10 for communication about measures eligible for accountability and pay for performance and 11 public reporting versus things that are not at 12 13 that standard or there's no standard 14 nomenclature you use? DR. BURSTIN: We refer to them all 15 16 as quality measures or performance measures. I think when we specifically refer to them 17 we're thinking about the measures appropriate 18 for consideration for NOF would be those that 19 20 would be appropriate and could ultimately be used for accountability and public reporting 21 22 programs. There may be other quality

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

3 DR. JENKINS: Thank you. 4 DR. BURSTIN: But, you know, it's 5 a really interesting distinction because many people that argue, because we say end quality 6 7 improvement it's an interesting lens through which to think of it. So for example we just 8 9 had a very interesting discussion with our 10 consensus standards approval committee about this issue of public reporting and 11 understanding what we mean by quality 12 13 improvement, for example. And so as an example we would, for 14 example, think of quality improvement measures 15 that would be reasonable for NQF to consider 16 things that would be reported to providers for 17 feedback and use and benchmarking as opposed 18 to many of the things we typically do in 19 practice kind of back of the envelope, QI, 20 keeping track of things. 21 22 Because again, there's a lens

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

DR. WINKLER: Just in terms of 3 nomenclature, when measure developers submit 4 5 measures for consideration by NQF, we actually ask them in its condition whether the measure 6 7 was developed and intended for the, you know, public reporting as well as QI kind of element 8 9 and if not, they really shouldn't be submitted 10 if they're truly that lower level QI kind of 11 measure.

12 And then from a nomenclature 13 perspective, actually once even endorsed by 14 NQF, they're known as voluntary consensus 15 standards.

16DR. LIEBERTHAL: Does NQF when17they approve or accept a measure require that18the measure has been tested in the real world19to see if it is both valid and feasible?20DR. WINKLER: Well, that would be21highly desirable, but it's been an interesting22journey over the last few years. And several

years ago there was a big push to get a lot of 1 measures out into the marketplace and a lot of 2 need by a lot of users, particularly CMS and 3 4 some of the other big payers. 5 And so NQF created a category, if 6 you will, for measures that were otherwise met 7 all the criteria with the exception of full field testing. And those measures could be 8 9 granted a time limited endorsement. That is something that still exists, we're evaluating 10 the utility of that. 11 12 It's been around now for about two

13 years, those measures have an automatic review 14 in two years to see and we're finding that a 15 large number, not large, we don't know, but a 16 significant number of them will either need to 17 be abandoned or revised. So we are learning 18 about this process.

19 Certainly I think it is most 20 desirable that the measures have -- that we 21 have -- it's hard to do a good evaluation if 22 you don't have some information around how

they perform in the field, particularly 1 2 outcome measures. So while it's not absolutely 3 required, it certainly is one of the 4 5 evaluation criteria and I would expect that a measure that hasn't been field tested would be 6 7 ranked fairly low on that aspect of the criteria. 8 9 DR. LIEBERTHAL: Has NOF or

10 anybody set a methodology, a standard 11 methodology for testing of measures? 12 DR. BURSTIN: NQF has a standard 13 protocol that we require measure developers, 14 who's measures come in as time limited to 15 follow. So they get up to 24 months to submit 16 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.

1	It's clear that some of it's too
2	stringent and some of them can't meet some of
3	those. And the other interesting complexity
4	as Reva mentioned all the work around health
5	IT, is that we're currently at the point where
6	many of our measures are now being, as we're
7	calling them, retooled for use in electronic
8	health records.
9	And testing in electronic health
10	records is a whole different beast that we
11	don't fully understand.
12	We've been having some of these
13	discussions, so you might, for example,
13 14	discussions, so you might, for example, create, and this is what many of the HR
14	create, and this is what many of the HR
14 15	create, and this is what many of the HR vendors do, an idealized EHR test set that you
14 15 16	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
14 15 16 17	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
14 15 16 17 18	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
14 15 16 17 18 19	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

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 8 9 the case a process measure, a simple, you 10 know, translation of a clinical guideline to a if then do something else. It's a little 11 bit easier to imagine than something perhaps 12 13 that requires adjustment or something like that coming forward and being untested. 14 15 DR. WINKLER: But an additional response to Allan's question is we do not have 16 any established method of testing the 17 questions on the evaluation and the submission 18 to the measure developers is open-ended. 19 20 Has the measure been tested for 21 reliability? How did you do it? What did you 22 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.

5 DR. RAO: Question over here. How 6 widespread are the measures used by non-CMS 7 payers, what's been the uptake of the 8 measures?

9 DR. WINKLER: I think it's 10 variable. Certainly we know that there are measures used within health plans, certainly 11 measures used within states. But actually 12 13 it's a very hard thing for us to get a handle on to really know, because certain areas, 14 organizations within Wisconsin, Minnesota, 15 Massachusetts, some of those states all sorts 16 of efforts around measurement. 17

18 So there's just lots happening and 19 most of those usually are using our measures 20 to a greater or lesser degree. But we don't 21 always hear about everything that's going on. 22 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 8 9 our current HHS contract, which this is funded 10 under as well, we're actually doing a formal evaluation assessment to begin to understand 11 what measures have been taken up and actually 12 13 why. I mean it would be helpful -- it's not just helpful to say who's using what, but why 14 were those picked up and those not and why are 15 some states still using a slight variation. 16

17 So this has been an interesting 18 discussion actually, Marina had to just step 19 out for her call, hopefully Charlie will join 20 us soon. We did some work for the work around 21 CHIPRA as they were kind of trying to figure 22 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 3 hospital oriented or condition specific, but 4 5 there's definitely a tension between what the state Medicaid programs for example, think 6 7 they're -- think they can reasonable accomplish and obviously Lee can talk much 8 9 more about this, versus perhaps some of the measures that we have. 10 So I think we're trying to begin 11 to understand that. We're also hoping to 12 13 build into our process going forward a really vigorous feedback loop so we can find out this 14 measure works well, this measure doesn't 15 really work well. 16 It may have been specified it 17 worked well in an idealized environment but 18 when it actually hits our hospitals, boy we're 19 20 picking up lots of unintended patients being put through that particular lens. 21 22 DR. PERSAUD: I have two

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1	questions, one does NQF have anything at all
2	to do with process improvement methodology and
3	do people do the users respond with these
4	are unfunded mandates?
5	DR. BURSTIN: NQF has not
6	traditionally been engaged in much of the
7	process improvement work with the exception of
8	our role as part of the National Priorities
9	Partnership.
10	So what they're doing with those
11	six national goals is they're to focus on six
12	aims which includes quality improvement,
13	payment, accreditation, the whole series of
14	IT, a whole series of various drivers of which
15	measurement, sort of our central focus, is
16	only one sixth, one of the six drivers.
17	So certainly the NPP is trying to
18	think through those process or improvement
19	steps. And on the other side of this, you
20	know, this is an interesting issue for us, we
21	put forward what we think meets a criteria, as
22	Reva will go over with you, but a fairly

stringent of measures that we think are 1 2 appropriate to compare apples-to-apples. That you're really getting a 3 reasonable assessment of somebody's 4 5 performance, allow end users to make better assessments, usable for people to make better 6 7 decisions. But we're not the ones who necessarily at the end of the say, pick which 8 9 measures get used. 10 So there's only, you know, to date a fairly limited role for us on the actual 11 implementation side. Some of that may be 12 13 evolving as health reform goes through or doesn't go through over the next couple of 14 months, but it's still an open question for 15 16 us. DR. WINKLER: Well that what I was 17 going to do is talk about the overall outcomes 18 project, that this -- it's Charlie. But I 19 think Marina would like to wait until she's 20 21 back so she can hear your introductions, so we'll still continue on. 22

1	Just to set the context, I
2	mentioned that this is part of a large project
3	funded by the Department of Health and Human
4	Services. We do have the three outcomes
5	steering committees. And so we will while
6	they have there area focus, there's certainly
7	areas of overlap.
8	Within the condition specific
9	areas that the main steering committee will
10	look at one of the topics is asthma. Well,
11	asthma certainly has a crossover for child
12	health. So we will be bringing some of those
13	measures both ways.
14	Right now actually we're not
15	finding a lot of asthma outcome measures, so
16	that's a bit of a struggle. And we can talk
17	about you know, perhaps are we looking under
18	the wrong rocks.
19	So I don't think it's really
20	critical that a measure has to be in one
21	versus the other. I mean we've got several
22	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

11 appropriate.

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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

1 important if that's your, you know, issue, but 2 certainly does not address the vast majority 3 of other issues that are appropriate for 4 children.

5 And I think that's really the We're going to talk about, a little 6 issue. 7 bit more detail when Marina returns, about those real -- the measures that we have, but 8 9 you're going to find that they really are 10 very, very narrowly focused such that it only captures a tiny group of the entire child 11 12 population.

13 So our goal with this project, to 14 the degree we're able and those measures exist 15 out there, is to expand NQFs current portfolio 16 of child health outcome measures. But the 17 focus is indeed on change order measures, so 18 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

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

5 What are they? What do they look 6 like? What do we -- what would we want in a 7 perfect situation, even if they don't exist 8 today. Go on the next. Okay.

9 Just to give you an overall view 10 of the bigger project that you're involved in, 11 this is laid out just strictly from a 12 management perspective in phases; phase 1, 2 13 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

21 20 condition into a topic areas that we're

22 looking at. We're looking at respiratory

1 conditions, particularly asthma and COPD, also 2 some intensive care unit measures, 3 cardiovascular, this is where we've got all 4 the measures, there are 19 candidate outcome 5 measures for cardiovascular, so, you know, big 6 area.

7 Metabolic, diabetes, chronic 8 kidney disease, not a lot of measures but if 9 you look at our existing portfolio we actually 10 have a large number of outcome measures around 11 diabetes already, not around chronic kidney 12 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.

18 That's why you're going to see 19 from the NQF perspective staff wise, there's 20 about -- there are five or six of us that are 21 actually on this project staff doing various 22 aspects of this project, so you may interact

1 with any of us at any given time.

2 DR. LIEBERTHAL: Quick question. Asthma was included in the phase 1, and of 3 4 those, asthma has both pediatric and adult 5 components. I've been on three measures groups for asthma totally dominated by adult 6 7 providers and allergists. Are we going to be dealing with asthma as a child health issue? 8 DR. WINKLER: I think we are. 9 Т 10 think there's really only one measure that's coming through that we've identified so far. 11 So I think in terms of this framework though 12 13 for children, if we want to look at specific conditions that are appropriate, and asthma I 14 think certainly would be on that list, we can 15 look and see how best to keep the measures 16 that appropriate for children in your purview. 17 18 DR. MCINERNY: Similarly, mental health problems are one of the major areas now 19 20 that we're dealing with in pediatrics and I'm wondering how are we going to interact with 21 22 the mental health team, because, you know, how

we treat kids with ADHD and kids with 1 depression and anxiety, et cetera that's 2 critically important and we need some outcome 3 measures for those conditions that are 4 5 children specific. DR. WINKLER: I think that at this 6 7 point we're flexible and open. A lot of it will depend on the input we get from you and 8 9 from the mental health steering committee, 10 which is meeting next week, as well as what measures get submitted to us for 11 12 consideration. And if necessary, we can bring 13 the two of you together to talk about common issues if necessary, kind of depends. 14 At this point, right now there's a 15 lot of unknowns in terms of what measures 16 we're actually going to get in front of to 17 deal with. And so it's great in the 18 theoretical, but when we have the reality of 19 20 what we're actually going to try and do, if necessary we can do a combined conference call 21 22 and, you know, learn from each other.

1	There's absolutely no reason we
2	can't do that. So I think we need to wait to
3	see what actually is going to get put in front
4	of us to understand that, but sharing the work
5	of the various committees where there's
б	overlap I think is an important part because
7	we really do want to foster the alignment, the
8	harmonization, we don't want things going off
9	in different directions without that.
10	So that's going to be one, I
11	think, the challenges for staff is to help you
12	get there. Well, time for introductions?
13	CO-CHAIR WEISS: So you have both
14	of us here now and I think all of our other
15	obligations have been discharged, right. So,
16	depending upon how you look upon it, you're
17	either fortunate that we'll be here for the
18	remainder of the meeting or you're stuck with
19	us. But in any event, Charlie Homer, have you
20	introduced yourself?
21	CO-CHAIR HOMER: I haven't. I
22	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 8 9 of you, as you're telling us a bit about 10 yourself and your background in measurement, we also need you to mention if you have any 11 12 involvement in measure development, any 13 particular interest in these specific measures as a disclosure to the entire committee as 14 well as for the record. So thanks for that. 15 CO-CHAIR HOMER: So in terms of 16 the record on that, other than those 17 committees, I do chair NCQAs Child Measurement 18 Advisory Panel on the new set of measures that 19 20 they're developing. Of course, I simply chair 21 that I don't have any other NCQA position. 22 And NICHQ actually did bring the

1	BMI measure initially to NQF so I think
2	somebody else may have taken over stewardship
3	of that. But that's our only official measure
4	steward job. We'll later on talk about the
5	other project which NICHQ is doing jointly
б	with NQF. So we'll cover that later.
7	CO-CHAIR WEISS: So do you want to
8	go in that direction and wind up with me or do
9	you want me to go ahead?
10	CO-CHAIR HOMER: No, of course.
11	CO-CHAIR WEISS: All right. Well
12	I'm Marina Weiss and I'm with the March of
13	Dimes and have been for a number of years.
14	And before that worked as an appointee in the
15	Clinton Administration, and before that was on
16	Capitol Hill, and before that was an academic.
17	So my passion, my greatest area of
18	interest is maternal and child health. I was
19	founding board member of NQF and have rotated
20	off the board some years ago, but continue to
21	be very interested in the quality agenda and
22	quality improvement as well as safety and

1 such.

2	And so was instrumental in
3	bringing my own organization into a steering
4	committee that led about 70 organizations here
5	in town and around the country and working
6	together with NACHRI and some others to build
7	a very robust quality section that, as I
8	described earlier, was included in the most
9	recent re-authorization of the Children's
10	Health Insurance Program and extends to
11	Medicaid as well as the CHIP program.
12	I don't know if any conflicts of
13	interest at all. This is just an area in
14	which the March of Dimes is now deeply
15	involved because of our interest in quality
16	improvement and safety. And so that's it.
17	MS. MARINELARENA: Hi my name is
18	Melissa Marinelarena and I'm the Project
19	Manager on the child health project. And
20	you'll see my name floating around with the
21	other outcome projects as well. I want to
22	thank you all for coming here and you'll be
1	

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

3 DR. WINKLER: I'm Reva Winkler. 4 I'm a project consultant to NQF now for the 5 last nine years. I'm an obstetrician 6 gynecologist by training and 20 years of 7 practice experience before coming to NQF nine 8 years ago.

9 I've been Project Manager for many 10 of the efforts that NQF has done particularly 11 around ambulatory care and consult on a lot of 12 our perinatal work as well. I'm overseeing 13 all of the outcomes work for the entire HHS 14 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

22 McInerny from Rochester, New York and I blame

Charlie for getting to this position here. 1 2 Way back, I forget how many years ago, we did HIPPO, not HIPAA, but HIPPO, H-I-P-P-O, 3 4 Helping Improve Pediatric Patient Outcomes, an 5 interesting project that Charlie ran through NICHO with collaboratives and our practice. 6 7 I really started as a primary care pediatrician and continued to be a primary 8 9 care pediatrician, but I moved over to 10 academia about 11 years ago. But our project was a great project on improving how we 11 provided care for children with asthma and we 12 13 really did I think have some good outcomes from that, we're still using a lot of that. 14 Then we did another project on 15 ADHD some years later, which I think worked 16 out well. And in my work now as Associate 17 Chair for Clinical Affairs in the Department 18 of Pediatrics working hard to make sure that 19 20 our inpatient and outpatient care at our 21 children's hospital is doing a lot of quality 22 improvement activities and we're making some

1 good progress there.

2 And I now have been on the steering committee for quality improvement for 3 4 about three years and learning a lot there, 5 working with a lot of good folks. And Allan's going to be joining us, which will be great. 6 7 He's actually on the committee already, but our first meeting will be next month. 8 9 I don't really have any conflicts 10 of interest other than the steering committee 11 on quality improvement. In that sum, there 12 are people like Allan and other people on the 13 steering committee as sort of a subcommittee they're doing some measures development. 14 But I'm personally not involved in that aspect of 15 it. 16 DR. RAO: Hi I'm Goutham Rao, I'm 17 at the University of Pittsburgh where I run 18 the pediatric obesity center and have done 19 20 that for about five years. Also teach clinical epidemiology and biostatistics at 21

22 Pitt Medical School.

1	This is my first NQF meeting and I
2	think I have to thank Charlie as well for
3	getting me here at some point. I don't have
4	any conflicts of interest.
5	I had served on an American Board
6	of Medical Specialties Quality Improvement
7	Committee around GERD and hiatal hernia, but
8	they're not very active right now; and a prior
9	committee similar to that from the American
10	Medical Association in about 2002, 2003.
11	So those are my connections to
12	quality improvement. Looking forward to this
13	meeting very much. Thanks.
14	DR. JENKINS: Hi everyone. I am
15	Kathy Jenkins. I'm from the Children's
16	Hospital in Boston. I am a cardiologist. I
17	actually have a history of doing measurement
18	development in the field of pediatric
19	cardiology and have developed a number of
20	measures.
21	In that regard, I am currently the
22	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.

5 And I do sit on the American College of Cardiology American Heart 6 7 Association combined performance metric taskforce. I do have one measure related to 8 9 cardiac surgical mortality that was -- my 10 methodology was partially incorporated into the PDI 6 measure that was put forward and 11 approved by AHRQ I think last year or the year 12 13 before.

14 And I am a measurement developer for one of the measures that the Children's 15 16 Hospital Boston put forward as part of the pediatric cardiac surgical program that was 17 discussed previously, though it's slightly 18 different than the AHRQ methodology. 19 In addition, I am the Chief -- as 20 Safety and Quality Officer for Children's 21 22 Hospital Boston and I've been in that position

1 for the last five and we have done a lot of measurement development for internal 2 benchmarking in that role for internal 3 4 purposes within the hospital and have been end 5 users to all -- in the pay for performance and Medicaid pay for performance work in 6 7 Massachusetts, which is a front runner state in this regard. 8 9 So I've both been at the front end 10 of measurement development and at the back end of measurement use in all of my various roles. 11 DR. SCHWALENSTOCKER: 12 Good 13 morning, my name is Ellen Schwalenstocker and I'm acting Vice President of Quality Advocacy 14 and Measurement for the National Association 15 of Children's Hospitals and Related 16 Institutions otherwise known as NACHRI. 17 18 NACHRI is a not for profit membership organization similar as Reva was 19 describing NQF, I'm like sort of the words we 20 use to describe NACHRI. About 200, a little 21 22 over 200 children's hospitals both

1 freestanding children's hospitals as well as 2 children's hospitals that are parts of larger systems as well as a third group of pediatric 3 specialty hospitals, primarily rehab. 4 5 I also am a liaison to the committee from NACHRI that Tom described, the 6 7 steering committee on quality improvement and management of the American Academy of 8 9 Pediatrics from NACHRI. NACHRI has a number of data 10 11 programs that Case Mix Program, for example, pulls administrative data and therefore serves 12 13 as a measure provider, if you will, for several of the Joint Commission ORYX measures 14 in terms of potential conflicts of interest. 15 We also have a system called the 16 Virtual Pediatric Intensive Care System which 17 -- through which in collaboration with a 18 couple of other organizations, including the 19 20 Child Health Corporation of America, we identified a set of initial pediatric critical 21 22 care measures that have been endorsed by NQF,

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

3 DR. CLARKE: I'm David Clarke from 4 Denver, Colorado and I practiced congenital 5 heart surgery for 30 years and then about five 6 years ago I discontinued clinical practice, 7 but continued with my interest in outcome 8 evaluation.

9 In the early 2000s after pediatric 10 cardiac surgery finally had a standardized nomenclature between Europe and North America. 11 I was involved in the development of a 12 13 complexity score which in with the lack of data was developed by consensus of about 50 14 surgeons, and this is related to cardiac 15 surgery procedures in the Quality Aristotle 16 Complexity Score. 17

18 It was in response to the trend 19 that was starting around that same time of 20 evaluating pediatric cardiac surgery based on 21 raw outcome data primarily raw mortality data. 22 And so basically what was

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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 6 also in combination with the RAC Score out of 7 Boston, the STS database began to accumulate 8 9 data along with the European Association for 10 Thoracic Surgery database and the risk adjustment for mortality and the Aristotle 11 Complexity Scores were applied to the analysis 12 13 for that data so that we finally got at least some risk adjustment into pediatric 14 cardiothoracic surgery. 15 So at this point in time it's 16

10 so at this point in the it's 17 okay. It's not perfect, but it's okay. We're 18 in the process of trying to validate the 19 Aristotle Score based on actual outcomes and 20 we have completed the evaluation of the 21 mortality score using approximately 80,000 22 patients from the European and the Society of

Thoracical Surgical Database and that should 1 be published any day now in the Journal of 2 Thoracic and Cardiovascular Surgery. 3 4 So from that standpoint I guess I 5 do have a conflict, although I have to add that the conflict is definitely not financial. 6 7 I work on the Aristotle Score and its maintenance on a voluntary basis. 8 9 I also have been fairly involved 10 with the STS congenital database. I serve on the database committee and am the Chairman of 11 what's called the data verification 12 13 subcommittee, which is responsible for performing randomized audits of five centers 14 around the United States that are participants 15 16 with the STS database every year. And at this point, we've been 17 doing that for three years and have completed 18 15 data audits and have found that for the 19 20 most part the data is very accurate but there 21 are some problems areas in terms of the difficulty collecting certain data fields. 22

1 I also do some institutional 2 review board work, so I'm involved in human research on that end as well. And I think 3 that's about it. This is my first meeting for 4 5 NOF. DR. PERSAUD: 6 Good morning, I'm 7 Donna Persaud and I guess I would be regarded as one of the end users of all this work that 8 9 we're going to do and that I am the Chief of 10 Pediatrics for a large safety net organization, it's Parkland Health and 11 12 Hospital Systems community oriented primary care clinics. 13 We have 11 clinics, we have 11 14 school based clinics in addition and we do 15 juvenile justice care as well as homeless 16 outreach and refuge. So we are a large 17 Medicaid practice. We do about 150,000 18 provider visits a year and about half a 19 million immunizations. 20 21 We have just installed EPIC and so 22 I am heavily involved in that development. We

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actually developed it -- we did not use EPICs 1 model system, we built it from ground up and 2 I think one of the most interesting things 3 4 that we did that I shared at the group here is 5 that we separated out the ages very discretely for health maintenance exams. 6 7 Whereas people often range those ages, we separated out the 2, 4, 6, 9, 12 and 8 9 I think that that has given us incisive 10 ability to respond rapidly to changes in what should be done at different ages. 11 12 What we're doing right now is 13 trying to extract data from the system to help us understand how we're using it and whether 14 we're promoting outcome. And I think that 15 EPIC was unprepared for the level and our IT 16 staff were unprepared for what we would want 17 to get from the system. 18 I just came in from Intermountain, 19 20 from Brent James Quality Training Program, we 21 just did our presentation, it was -- my

22 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.

5 And we actually demonstrated 6 results and so I've got a lot in my mind. I 7 think this is exciting and interesting. I 8 have no prior involvement in formal setting of 9 measures, although it is a high interest of my 10 system.

We're looking at both individuals 11 and moving the populations in an urban 12 13 environment towards health. And we're trying to think beyond just traditional straight 14 primary health care and we think the children, 15 especially with the obesity epidemic, are in 16 such need under other models of care that can 17 move the population towards wellness faster, 18 because we're concerned that getting every 19 20 child in for primary care visit on schedule 21 might not practically be able to do that. 22 So thank you for the opportunity.

How did I end up here, someone from Parkland 1 saw the request, the CMO called me, my CV was 2 sent and that was it. 3 And I'm Bonnie Zima and 4 DR. 7TMA: 5 I think I'm the only child psychiatrist here on the committee. And so I was really 6 7 interested in your question and I'm very much wondering whether there's a child psychiatrist 8 9 on the mental health committee as a buddy. 10 DR. PERSAUD: More than one 11 hopefully. 12 DR. ZIMA: Is there a child 13 psychiatrist on the mental health committee? DR. WINKLER: I'll have to double 14 I'll get the roster for you. 15 check. DR. ZIMA: Okay. And the way I 16 came on this was actually I was on the APAs, 17 the American Psychiatric Association's 18 committee on quality indicators and their 19 20 Chair saw the announcement and then also Larry Greenhill at Columbia, who is the President of 21 the American Academy of Child Psychiatry also 22

1 supported my nomination.

2	So I think we're clearly in the
3	infancy of developing quality indicators. I
4	have no conflicts of interest. I'm proud to
5	say I've never taken any pharmaceutical
6	industry support for any of my research.
7	I've been funded predominately by
8	the NIMH as well as the state of California
9	through contracts. I'm not only a child
10	psychiatrist, but a health services researcher
11	and my main role at UCLA is really Associate
12	Director now of the Health Services Research
13	Center.
14	I'm not Associate Director of the
15	whole department as stated in the materials
16	and I don't think I want to be. And my
17	introduction to quality of care was really an
18	opportunity that was really I think kind of
19	groundbreaking and that was several years ago
20	Dr. Steve Mayberg who is the Director of our
21	state department of mental health had some
22	left over money and to the tune of \$1.5

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1 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.

7 So it was really amazing because we developed a collaborative infrastructure 8 9 pretty quickly across five universities within 10 California, developed this strategy, developed 121 quality indicators for the assessment and 11 treatment of ADHD, major depression, conduct 12 13 disorder, applied it to a statewide sample of children in 22 clinics in 58 counties and used 14 the episodic care methodology. 15

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 itvary by race, ethnicity, gender, things like

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1 that. The answer was no. If the kid got into 2 care and stayed into care for at least three 3 visits, there was no variation. There was 4 also big issue, and I think this gets back to 5 the whole issue of understudied kids in 6 Medicaid.

7 In the state of California what happens is that each county can decide whether 8 9 they're going to use their Medicaid money to 10 fund directly operated clinics or contract So one of the big issues on a policy 11 out. level was where does quality care vary, was it 12 13 better to have it in a directly operated clinical or contracted out clinic. 14 And the bottom line was we 15 couldn't pick up any difference. So all of 16 this work then led to an R01 that we have some 17 findings that are going to go under review 18 next month asking the question of quality of 19 20 care for ADHD in managed care Medicaid program 21 in Los Angeles. 22 And what's important about that is

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I think it's the first study looking at 1 quality and primary care and specialty mental 2 health, okay. And right now we also have an 3 R34 looking at development of a web-based 4 5 clinician decision support tool to do a better job engaging parents in the process of 6 7 medication treatment decisions. It's a very sensitive issue when 8 9 you're using psychiatric meds and also again, 10 seeing whether we can improve safety and appropriateness in medication. And again this 11 is all focused on Medicaid funded programs. 12 13 So I think that's it. 14 MS. PARTRIDGE: I'm Lee Partridge. I'm the Senior Health Policy Advisor with the 15 National Partnership for Women and Families, 16 which is an old consumer advocacy 17 organization, particularly concerned about 18 health care and job working environments, 19 health care benefits, harassment, et cetera. 20 We started out as the Women's 21 22 Legal Defense Fund back in the Civil Rights

days to work particularly on that last issue, 1 workplace issue, but over the years we have 2 more into a very, very deeply involved 3 4 organization around health care quality 5 particularly in respect to women and families and in my case, very definitely woman and 6 7 families of lower income. Because I came to the partnership 8 9 from 25 years in the world of Medicaid and I 10 do remember Dr. Mayberg, you were very fortunate to have him in California. 11 T was the Medicaid director here in the District of 12 13 Columbia from 1983 to 1992. We are a medically rich, a very 14 medically rich community with a major 15 children's hospital. The population I served 16 was heavily Hispanic and African American and 17 of course, very interesting differences in the 18 pediatric quality of care for those children, 19 20 I might say Hispanic and African American. I then went on and worked with the 21 National Association of State Medicaid 22

Directors for 10 years and was part of the 1 founding board, as a purchaser as a matter of 2 fact, as an alternate member of the founding 3 board of NOF. 4 5 I have been working with NQF now 6 as long as Reva has. I co-chaired the very 7 first nursing home standards committee which was an education for all of us I think. And 8 9 I have been most recently a member of the 10 perinatal measures committee, which reported measures out last winter. 11 I don't believe I have any 12 13 conflict of interest financially. I should share the fact that I too am in the NCQA Child 14 Health Steering Committee and I am currently 15 chairing the Medicare Health Plans 16 Accreditation Committee for NCOA. 17 And we, of course, looking at both 18 the current standards for health plans that 19 20 participate in the Medicaid program as well as the clinical measures that are being used in 21 22 the accreditation of those programs.

	1
1	DR. DOCHERTY: Hello I'm Sharon
2	Docherty. I'm an Associate Professor at the
3	Duke University School of Nursing where I
4	direct the pediatric acute and chronic care
5	nurse practitioner program. I spend the
6	majority of my time conducting research.
7	I have several NIH funded studies
8	centering around issues related to the quality
9	of life of infants and children undergoing
10	life sustaining treatments for life
11	threatening illnesses.
12	Our most recent award is that we
13	have a five year study we're looking at
14	decision making with providers and parents of
15	infants born with life threatening illnesses.
16	I practice as a pediatric nurse
17	practitioner in the Duke Children's Hospital
18	mainly with chronically ill children and I am
19	here representing the National Association of
20	Pediatric Nurse Practitioners.
21	And I don't have any conflict of
22	interest. The only thing I can think of is

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I'm working on a measure right now to measure 1 technology dependence in some of the children 2 that we're studying. I'm happy to be here. 3 4 DR. LIEBERTHAL: I'm Allan 5 Lieberthal. I'm a primary care pediatrician and clinical pediatric pulmonologist at Kaiser 6 7 Permanente in Panorama City, California, which is in the San Fernando Valley about 10 miles 8 9 north and one hour during rush hour away from UCLA where Bonnie is. 10 I'm the new member of the AAP 11 12 steering committee on quality improvement and 13 management and was nominated by the AAP. I've also been on the measurement interest group 14 subcommittee of that committee for several 15 16 years. I was co-chair of the PCPI 17 committee that wrote the acute otitis externa 18 and OME measures and I've been working with 19 20 Carole Lannon studying the utility of those 21 measures, a study that's nearly complete. I'm also involved in evidence-22

1 based medicine, I was the co-chair of the 2 original acute otitis media guideline committee for the AAP and now I'm chairing the 3 revision of that guideline committee and I 4 5 also chaired the AAPs bronchiolitis guideline committee. So I have been involved in quality 6 7 -- measurement work.

I've also been a member of the 8 9 NCQA asthma measures committee and those 10 measures are now available for public review. And I'm sitting on a Robert Wood Johnson 11 Foundation panel that's looking at asthma 12 13 measures and their application for attribution of costs, and that's an ongoing committee. I 14 have no financial conflicts. 15 16 DR. BURSTIN: What a great I'm Helen Burstin again, I'm the 17 committee. Senior Vice President for Performance Measures 18 at NOF. I oversee all of our work related to

20 practices, measures, frameworks as the case

21 may be.

22

19

I'm coming up on my three-year

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anniversary at NQF actually in January. 1 Ι 2 feel like I still just arrived. Before that I was at AHRQ for seven years where I directed 3 the Center for Primary Care and Prevention in 4 5 Clinical Partnerships, oversaw the work of U.S. Preventive Services Taskforce. 6 7 I'm an internist by training and I still see patients on Friday mornings at a 8 9 Latino health center here in town. DR. MCINERNY: Allan reminded me I 10 am an AAP representative to the AMA PCPI and 11 12 I have attended those meetings fairly 13 regularly. I've been a little disappointed that with just a few, only a few measures that 14 they've really considered have applied to 15 children. Of course they're largely looking 16 at adult measures. So I'm glad that we have 17 this group. 18 And I wanted to ask a question 19 because I know that the Chair of the Steering 20 21 Committee on Quality Improvement, Javier 22 Sevilla has sat on the AHRQ CHIPRA committee

1 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 8 9 the group that I spoke about earlier and the 10 task was to get a set of recommendations together for the Secretary's consideration in 11 meeting the requirements of the Children's 12 13 Health Insurance Re-authorization section on 14 quality.

15 That deliberation is currently 16 underway as I understand it, at HHS and they 17 are under obligation, the law calls for them 18 to publish the first core set at the beginning 19 of the month of January of 2010.

20 But one of -- I also sat on that 21 committee with Javier and one of the things 22 that we did was to tier our recommendations.

1 And yes there was a set of 25 very 2 specific performance measures that we put on 3 the table, but we also hope we signaled to the 4 community at large that there were other areas 5 that we felt merited further consideration and 6 additional work.

7 And that is wave 1 or phase 1 of what we hope is a more comprehensive process 8 9 in looking measures. The emphasis in that 10 core set was on what's out there right now 11 ready to go and where are these measures currently being used at the state level in the 12 13 Medicaid and CHIP programs and therefore recognizing that that time frame is pretty 14 short, could we get these performance measures 15 up and operational in more venues across the 16 country very quickly. 17

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

21 CO-CHAIR HOMER: Is there anyone 22 on the phone?

1 MS. PERKINS: I'm Jane Perkins, 2 I'm here. 3 Would you like to CO-CHAIR HOMER: introduce yourself please? 4 5 MS. PERKINS: Sure. I'm the legal 6 director at the National Health Law Program. 7 Most of my work here over the last 25 years has focused on the Medicaid program, in 8 9 particular EPSDT. I've done writing on this 10 and engaged in policy and litigation on the 11 EPSDT program. 12 I came to quality measures and 13 I've sort of darted in and out of them over this period of time. But particularly in the 14 late 1990s when I was on a working group that 15 HCFA and the National Academy for State Health 16 Policy sponsored on QZMC ***11:29:47. 17 18 Then in the early 2000s I was on a steering committee that was looking at 19 20 external quality review organizations and their role in improving quality and was sort 21 22 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.

4 We have over the years included 5 and tried to aggressively include performance measures in the litigation that we have won 6 7 and have, whether it be measure of lead testing or Body Mass Index and have tried to 8 9 have measures that would apply not only in 10 cases where we've been trying to get 11 preventive and screening part of EPSDT working, but also the treatment part of EPSDT 12 13 working and with a particular focus on children with special health care needs. 14 Obviously, as you all know, it can 15 be getting something on the piece of paper is 16 so very difficult and then having all of the 17 different managed care companies using their 18 own computers that measure things differently 19 20 can be just a screaming headache. 21 So I was very drawn by your

22 comments earlier as you're giving your

presentation about harmonizing and making 1 these measures ones that will be -- have 2 somehow a maximized value to providers so that 3 4 they will use them and want to use them. And 5 that's it. Thank you Jane. 6 CO-CHAIR HOMER: 7 DR. WINKLER: Anybody else? MS. PERKINS: I appreciate your 8 9 having me on the phone by the way. I really 10 appreciate this accommodation. 11 DR. WINKLER: Thank you Jane. Is there anybody else on the phone? We weren't 12 13 sure who else might be calling in. CO-CHAIR HOMER: Did we want 14 members of the audience? 15 DR. ZELL: I'm Bonnie Zell. 16 I'm Senior Director for Population Health at NQF. 17 18 MR. CORBRIDGE: Good morning everyone, my name is Ian Corbridge. 19 I'm, I 20 guess, Project Manager for the mental health project. I'm just sitting on today kind of 21 seeing discussion, it also sounds like there 22

might kind of be some collaboration that we 1 need to do with this group as well as the 2 mental health group. 3 So anything that we can do to help 4 5 facilitate that, that's what we're here for. So thank you very much and have a good day. 6 7 CO-CHAIR HOMER: Terrific. Thank you. Well, it looks like we're actually quite 8 9 -- are we -- well -- Reva, have you not finished? 10 11 DR. WINKLER: No. 12 CO-CHAIR HOMER: Oh, okay I'm 13 sorry. I thought you -- I heard such a wonderful project overview when I was walking 14 in. So let us return to the project overview. 15 DR. WINKLER: Thank you, now that 16 we all know each other. I asked Melissa to 17 put this slide up. You should all have this 18 in your materials and these are the outcome 19 20 measures that have been endorsed by NQF. And this is where I'm going to ask 21 you to start thinking because I think if you 22

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look at this, and there were more than I 1 realized, somebody counted them and said there 2 were 25 of them, but I think if you take a 3 look at them, you'll see that they really 4 5 don't have a whole lot of rhyme or reason as 6 an organizational group. 7 They kind of came to us in multiple projects, you know, a couple here and 8 9 a couple there and a couple here and there and 10 here was what we got. And so at the end of the day, it isn't a very cohesive set of 11 12 measures. 13 And one of the things, even though they're all outcome measures, important, 14 address very important issues, one of the 15 things that we really would need your help on 16 is understanding how do we figure out where 17 these fit in and what are the ones we don't 18 19 have that we truly need. In other words, sort of the 20

21 organizational structure, the framework, how 22 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.

5 And we either need to find 6 existing measures if they exist or, you know, 7 really try and promote the measure development so that we plug the holes so that at the end 8 9 of the day, rather than having a mish-mash of 10 this, like we do now, we are working towards a coherent organization of outcome measures 11 that meets a variety of needs. 12

13 So we need to understand what the 14 dimensions are, we need to understand what 15 those domains should be and, you know, whether 16 it's a two dimensional grid or if it's several 17 two dimensional grids that you slice and dice 18 the issues in a variety of ways, great.

19 That's really one of the biggest 20 things you can help us with understanding for 21 this project. It will drive both our call for 22 measures and it will drive our analysis on

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1 measures that we need but don't yet have. 2 So keep in mind as we start talking about things, how might we figure out 3 what that sort of big thing looks like that we 4 5 can plug the measures into and then figure out where the holes are. So that's kind of what 6 7 we're working on today. So this should be a reference, and questions at all times. 8 9 DR. MCINERNY: I'm going to share 10 my primary care bias. Although certainly measures for children that are hospitalized 11 are important and they often are expensive in 12 13 terms of their morbidity, mortality and dollars. 14 We have to keep in mind that a 15 very, very small fraction of children end up 16 in the hospital at any given time or during 17 their lifetime for that matter and that I 18 think most of us would agree that it's the 19 outpatient care for children that's so 20 21 critically important and how we provide that care for children, the quality of care we 22

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

And so my plea would be that, you 3 4 know, we look and maybe perhaps slice and dice 5 you talk about outpatient outcomes, very important and try and get a significant number 6 7 of those that we can agree on and, you know, we can do some of the inpatient outcomes, but 8 9 the numbers are so small that you're not going 10 to affect the vast majority of children with 11 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 1 know, outcome measures for outpatient care. 2 That's probably a little too 3 We need to be a little bit more -vaque. 4 5 have a better understanding of what those 6 might look like and the various types of 7 outcomes. And we've got some ideas to just 8 9 offer to you as a place to start, but we're 10 hoping this afternoon this will be a discussion that you'll entertain. 11 12 And we can do some serious 13 thinking around how do you want to organize this so that we can at the end of the day be 14 able to convey this information to others an 15 get the outcome for the project that we're 16 looking for as well as improved outcomes for 17 kids. Any other questions? 18 DR. JENKINS: Well just in terms 19 20 of brainworks, although I think to your point 21 about ambulatory measures, the scope and locus could be very different. We sort of went 22

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1 through this exercise five years ago for 2 Children's Hospital Boston and ended up choosing the Institute of Medicine STEEEF 3 criteria as our overall framework and I must 4 5 say having watched it evolve over five years it's worked awfully low. 6 7 So I would just offer that up and could show what, you know, how that kind of 8

9 looked and how a lot of the ornaments hung 10 very nicely under that tree, so.

11 CO-CHAIR HOMER: I have a 12 technical comment, which is I think the 13 pediatric diagnosis column in here must be 14 pulling from some other peculiar database 15 because it's irrelevant. So in the next 16 version of this just get rid of that field 17 it's random.

18 MR. CORBRIDGE: I have a comment 19 for that, somehow when we were clearing the 20 fields it seems to be sorting alphabetically 21 instead of by the outcomes or process. So I 22 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 4 5 phone, I'm sort of going through the slides looking for the list of them and I'm having 6 7 trouble coming up with it. Let me just ask a quick question and that is, are all of these 8 9 measures outcome oriented as opposed to 10 process oriented? DR. WINKLER: Yes, Jane, I'm 11 12 sorry. We flipped over to the bundle of 13 materials that was sent to you as the large PDF and it begins on page 10. And yes indeed, 14 this list is all outcome measures 15 16 intentionally. There is an additional list of the 17 process measures just for completeness, but it 18 starts out with all of the outcome measures. 19 20 So you do have that in the large PDF bundle of 21 information that was sent out to you. 22 MS. PERKINS: And will we -- so is

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this group to focus on both or just the 1 2 outcome? DR. WINKLER: This is all about 3 4 outcomes. 5 MS. PERKINS: Okay. DR. WINKLER: 6 Okay. So Melissa 7 you can go back to the slides now. Jane we're going to go back to the slides and I'll start 8 9 with slide number 25. 10 MS. PERKINS: Okay. Yes. DR. WINKLER: I'll try and stay as 11 oriented there. So, we did mention that there 12 13 are some measures around pediatric cardiac surgery, again another hospitalized narrow 14 condition area that are in the pipeline. 15 So the actual number of outcome 16 measures will change in another couple of 17 They are going through the consensus 18 months. process which we will talk about. Next slide. 19 But essentially, you know, NQF has 20 experienced the challenges around measuring 21 for child health. The emphasis on most of the 22

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

Certainly the funders of our 3 4 projects have been those who deal with older 5 adults, we've done a lot of work for CMS and 6 so you kind of get the expected results. 7 So the children -- measures for children do represent, you know, a relatively 8 9 small group of all of our endorsed measures, but we do have some issues around measurement 10 for children that we have to sort through. 11 12 One is inconsistent definition of 13 children. You know, what's a kid? Age inclusion. Sometimes it's appropriate for the 14 condition, but sometimes it's just an 15 arbitrary, you know, definition and that does 16 make it hard for the set to have any kind of 17 cohesion to it. 18 Inconsistent application of 19 20 crosscutting measures. There are a lot of 21 measures that are created that really aren't 22 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.

5 And so there's no reason it can't 6 be applied to children, but they just don't do 7 it. So these are some of the issues that have 8 made it hard so that there could potentially 9 be more measures appropriate for children, but 10 for whatever reason kids just don't get added 11 to the mix.

12 So also in terms of outcome 13 measures, overall outcomes is sort of the later measures in development. We're starting 14 to see an upswing in them, but like 15 everything, you know, children, measures for 16 children fall even further behind. 17 18 So, you know, these are the struggles and challenges, but I think that we 19 20 should be able to -- we've already identified, 21 you know, a group of measures, we should 22 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 3 what kinds of measures, what should they look 4 5 like, what should they about so that we could take those to the measure development 6 7 community and really get some traction on getting those measures developed. So that is 8 9 a huge goal for this project as well. 10 So let's just look at the measures we've endorsed for children, and again, most 11 12 of these are around processes. And you can 13 see that they tend to be some prevention and immunization, but it's mostly the immunization 14 15 measure. 16 Some patient experience with care measures, actually there are three or four 17 that are appropriate for children and 18 particularly around adolescents. 19 20 Within our perinatal set of 21 measures, some of them very specifically

22 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 4 5 measures in certain condition areas. And Marina's already suggested that we need to get 6 7 the list of the top 20 conditions for children to factor in this. We could probably figure 8 9 out what they are, but the question is, is it 10 by volume or by cost. You'll tell me and we'll figure that one out. 11

12 We've got inpatient measures 13 certainly and we have -- and then the question around safety measures. So, there are many 14 15 ways of describing outcome measures and again, this is where we need your help what's the 16 best way to do it so that we can describe to 17 a large audience, you know, where we are and 18 19 where we want to go. 20 So among the prevention measures 21 you can see them. Charlie takes ownership for

you can see they're kind of across the board, 1 a little smattering, you know, a couple for 2 adolescents, a couple for newborns and a 3 little of this and that. I mean they're not 4 5 very cohesive so we need to think around how do we make this approach cohesive. 6 7 I mentioned that the patient experience with care, we do have several 8 9 versions that are appropriate for kids. So 10 these are endorsed measures so these are nice, we do have this area covered. But if there 11 are other good measures out there that we need 12 13 to deal with, we certainly don't want to overlook them. 14 The next one is our perinatal 15 Lee and I both worked on this 16 measures. project and several of the measures are 17 appropriate measures of the newborn neonatal 18 period. But again, this is a hospitalized 19 focused effort, so it does have those 20 limitations. 21 22 The next one, where are we on

1 outpatient measures. You can see we've got some for asthma, one for diabetes, a handful 2 for ADHD, you know, otherwise again, mish-3 4 mash, not something that really describes health care for kids. And these are primarily 5 6 process measures. 7 So, and then of course we talked about the inpatient measures. Okay. So again 8 9 it's a bit disjointed, it came to us -- it's 10 the result of years of various activities and

11 here we are.

12 So we need to deal with the group 13 of measures for kids in a systematic way, if 14 you will. So NQF has several avenues to try 15 and make our portfolio more appropriate for 16 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

1 to whatever is appropriate.

2	Outcome measures for children,
3	that's why you're here, okay. So among all of
4	NQFs activities around child health, this is
5	an important part of it. More outcome
6	measures for kids and again, at the same time
7	of any of our other efforts, measures
8	applicable to the NPP national priorities and
9	goals that are appropriate to children.
10	So we have all of these
11	overlapping dovetailing events, but this group
12	is in a position to help us identify existing
13	measures or identify the measures that need to
14	be developed that really can bring all of
15	a lot of these together and fill some very
16	important gaps in the portfolio for
17	measurement for children. So, next.
18	So as I mentioned, these are our
19	project goals. We are going to be calling for
20	measures to be submitted to this project for
21	you to evaluate and consider and potentially
22	recommend for endorsement.

1 In January, one of the things we're going to specifically ask you to help us 2 with and I'm going to lay it out there now so 3 vou can think on it, is where do we target 4 5 that call for measures to be sure the people who need to hear it, do hear it. 6 7 We have our usual avenues, you know, we send it to all of our members and we 8 9 post it on our website and all this other good 10 stuff, but we know that there are likely to be folks out there who many not get the message 11 that way and you all potentially have contacts 12 13 you know, that's the world you live in. Help us be sure that the message 14 and the word gets out so that the measures 15 that exist and are out there get submitted to 16 the project. If we don't have them to work 17 with, we're not going to be very happy with 18 the end result. 19 20 So that's sort of assignment number one and we'll, you know, think on it. 21 22 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 3 those, it would be nice if we had a group of 4 5 measures, I don't know, are there six of them out there, are there 60 of them out there? 6 Ι 7 don't know, perhaps you have a better idea and you can tell us measures that we haven't seen 8 9 already or that are not already on the list 10 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

17 offer that we do a regular surveillance of the 18 landscape we call it the state of the universe 19 of pediatric measurement in children that we 20 have somebody updating.

21 And I would be more than happy to 22 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.

7 DR. WINKLER: We are certainly 8 eager to see any of the resources you all 9 might be using in your lives to help pull this 10 together. That's why we use you to really 11 help understand to get out into that world 12 that you all work in so that we can be sure 13 that we're as comprehensive as we can be.

So I mentioned we'll do that call 14 for measures so then your role will be to 15 16 actually evaluate those measures. NOF has standard measure evaluation criteria and we're 17 going to go through those in some detail so 18 that you understand them and have the 19 20 opportunity to ask questions about them and about that evaluation process. 21 But then as I keep mentioning and 22

I want to emphasize, as an equally important 1 part of this project in terms of the goals, is 2 creating this organizational structure, the 3 framework if you will, to help us understand 4 5 where the gaps are, identify them such that we 6 can say we need measures, we need measures of 7 functional status for kids with X, whatever, I mean you tell me. 8

9 But how do we figure out where 10 those gaps are, how do we describe it, how do we explain this to folks to get the message 11 out there that makes it very straight forward 12 13 what we're looking for and that it's not ambiguous and it's not so generic that, you 14 know, we don't get what we want in the near 15 16 term, because that will be very important. 17 Next one.

18 The keystone of what NQF does is 19 developing consensus. And endorsement of 20 measures is through our formal consensus 21 development process and I just want to go over 22 that briefly because you are overseeing that

process, so I'd like you to be familiar about 1 2 what it is. It is a formal process, the 3 4 consensus that we built pays attention to our 5 overall strategy for measuring and reporting within NQF, multi-stakeholder membership, 6 7 you've heard that around the table, that's deliberate, intentional and a necessary part 8 9 of the work that NOF does. We want -- we include both 10 11 private and public sector to the group possible, we want to look at the entire 12 13 continuum of care. Okay, so particularly even 14 though we're narrowed -- narrow ourself to 15 outcomes, it's outcomes from any aspect of 16 care. So some of our projects are 17 focused in on hospitals or they've been on 18 outpatient. This isn't so much studying 19 20 specific as it is the outcome measures rather 21 than all measures of the type. So there are 22 many ways we've organized some of our

1 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.

9 This process actually comports to 10 federal law, the 1996 National Technology and 11 Transfer Advancement Act, 1996 as well as OMB 12 Circular 119 which defines voluntary consensus 13 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

19 last 10 years we have enjoyed a very good 20 relationship with our friends in the federal 21 government. They are actually funding this 22 project and the work we're doing and so much

1 of the work we've done over the last few
2 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.

8 The steering committees role, and 9 we'll go over some of the more details, but 10 you oversee it. You help us make sure that we 11 reach both the project goals as well as follow 12 the consensus development process.

13 So we constitute the steering 14 committee as a multi-stakeholder group. You are the decision making body, you do represent 15 -- you're the proxy for the NQF membership. 16 Remember the 400 members? Well we can't put 17 them all in a room and have them talk, so we 18 19 brought you as representatives as a proxy for 20 them.

21 But we do want the perspectives 22 from all the various stakeholders that's a

1	critical aspect of the work that NQF does.
2	So essentially what we'll be doing
3	is reviewing the measures that get submitted
4	to the project according to standard criteria.
5	You will then be making
б	recommendations, which measures should go
7	forward for endorsement as well as
8	recommendations on things like which measures
9	need to be developed, the framework that we're
10	going to establish to say this is how we want
11	to look in child outcome measures and, you
12	know, we've got these, but we need these.
13	All of those will be
14	recommendations from this group back to the
15	NQF membership and sort of the world at large,
16	and those are the draft recommendations. We
17	package it up into sort of a standard format
18	report and then it goes out for public
19	comment, a 30-day NQF member and public
20	comment.
21	We have developed a mechanism
22	where those comments are submitted

electronically and then they get folded into 1 an Excel spreadsheet. We will come back to 2 you, how do we respond to these comments, look 3 4 at the comments. Sometimes they just 5 reiterate things we've already talked about, that's very common. 6 7 But sometimes you will have three, four, five, six organizations sort of with a 8 9 theme that disagreed with something you did or 10 think you didn't go far enough or whatever. 11 So, you want to potentially reevaluate some of your recommendations in 12 13 light of those comments. And we do take the comments very seriously so we'll be coming 14 back to you, we'll have a conference call, 15 we'll pull out the things that we think you 16 really need to pay attention to or you can 17 pull out things you think that need to be, you 18 know, redone. 19 20 And so the comment period is 21 really important one because it's a dialog. You're creating a set of recommendations that 22

at the end of the day is a product of NQF. 1 You're acting as the representatives of the 2 much larger group, so you get their input. 3 Once we have reconciled the 4 5 comment period, the review and comment period, we then create a final report, and this is now 6 7 the draft consensus standards that goes out to the NQF membership for voting, all right, they 8 9 all get to vote, one of the benefits of 10 membership is voting. And the results of the voting and 11 any comments that are submitted are taken to 12 13 the consensus standards approval committee, which is a subcommittee of the board. 14 The board actually grants 15 endorsements so they have designated a 16 subcommittee to do the focused work around the 17 measure endorsement process. So they look at 18 the work that was done, be sure that we follow 19 20 the consensus process, really look at the 21 comments, really look at the general information that's come. 22

1	Each project has its own
2	character, it has its own set of issues around
3	it so they try and be sure that the process
4	and the end product is really optimal to NQF.
5	And they make the recommendations
6	to the board and the board ratifies them for
7	the final endorsement as voluntary consensus
8	standards. Then, there's a 30-day appeals
9	period after that.
10	So all of those steps are
11	important and they are rigorous and they are
12	not flexible to allow us to maintain the
13	integrity of the process. But as I said,
14	you're an integral part of it, we will be
15	keeping you, you know, the biggest amount of
16	work for you guys is up front when we do the
17	draft evaluations and the draft
18	recommendations. What do you want to tell
19	people we should do?
20	That will be the most that will
21	probably be the most intense work, but you
22	will certainly be involved in the review of

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

Let's see, when are we due for 4 5 lunch? Okay, thirty minutes until lunch, can you hang in there. Are they ready at all 6 7 earlier? Okay. All right. So are there any questions in terms of that? I'm going to go 8 9 into some of the details, but I wanted to hit 10 the high points so that you know what you got yourself in for. What did you volunteer for 11 12 really.

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

Again, it's another 16 DR. WINKLER: one of those we have the dissemination 17 avenues, it's posted on our website, we do 18 send it, information out to all of our 19 20 members. Helen are there any other avenues 21 we're using for announcing public comment? 22 DR. BURSTIN: There's also a

weekly blast that goes out to the public, very 1 2 wide distribution, it's also on our website. And, you know, at least the last project Reva 3 4 led on clinically measures we got 800 5 comments. So that part of that process is --DR. WINKLER: Yes, from about 100 6 7 different --8 DR. BURSTIN: -- very robust. 9 Yes. 10 DR. WINKLER: Yes, it can be. It isn't always, but it can be. 11 12 MS. PARTRIDGE: I would also add 13 that the various the eight councils to some degree take some responsibility for reaching 14 out to people that they think might be 15 interested. 16 When we did the perinatal 17 measures, for example, the National 18 Partnership who collaborated with Childbirth 19 Connection, which is -- their director Maureen 20 21 Corry was change order-chair of that project and using our combined e-mails and websites 22

and so on, we tried to reach lots of people we 1 2 thought wouldn't necessarily know about through the traditional route. 3 4 And I'm afraid as a result, we're 5 creating a lot more work for NQF. I think you're going to get a whole bunch of care 6 7 coordination, Reva. DR. WINKLER: Public comment is 8 9 public comment. But again, this would be 10 another role for you all because we will let you know it's now posted for public comment, 11 go here. You can take that e-mail and send it 12 13 to anybody you want to that you think would be 14 interested. 15 So you guys are tied into the real child health community and can be a real asset 16 in further dissemination so that we are 17 hearing from the folks out there in terms of 18 how it's playing in Peoria, if you will. 19 So 20 again, these are the kind of roles for you to 21 play as we go through this process. Any other 22 questions?

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Page 126 1 DR. MCINERNY: Do, for instance, 2 are part of the public the state Medicaid directors and medical directors of major 3 4 payers, insurers that are particularly 5 interested in child health? Yes? 6 DR. WINKLER: I guess I'm not sure 7 exactly what your question, when -- you're asking are they involved? Yes, they certainly 8 9 would be. 10 For instance, the Association of State Medicaid Directors is one of our 11 members, you know, to the degree that they 12 13 then distribute it to all 50 or however many state Medicaid directors, Lee can probably 14 15 speak to it. That was one of the things she, you know, established before she went to the 16 National Partnership I would guess. 17 18 MS. PARTRIDGE: Yes, actually the Secretary of Health and Human -- I forget what 19 20 the departments are called in Michigan, but she's on the NQF board, there's traditionally 21 been a seat for Medicaid on that board. 22 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 10 were talking about, the AHRQ committee and 11 they -- when I was Medicaid director, we 12 13 tended to have part time medical directors, many of them people who had given up 14 practicing and wanted to kind of keep their 15 hand in, but they really -- most of what they 16 did for me was work on approval of transplants 17 and special procedures and so on. 18

19 There's a new breed out there 20 right now increasingly young doctors who make 21 this a career and are career members of their 22 state health departments or state Medicaid

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

DR. MCINERNY: To sort of follow 3 4 up, for the major national insurers, I'm not 5 sure how we can ensure we've gotten the attention of the medical directors in those 6 7 organizations that would have overview of the children's health part of their programs. 8 9 Because frankly, my experience is 10 that it's difficult to get their attention, medical directors insurers attention about 11 children's health. They seem to be want to 12

13 concentrate on adult health, that's who's 14 measures for lots of reasons.

15 So I just want to try and ensure 16 that somehow we get their attention and then 17 they pay attention and follow through. I 18 don't know Charlie, maybe you can --

19 CO-CHAIR HOMER: No, I think it's 20 a great point. It's certainly an issue we've 21 wrestled with for a long time. I think to the 22 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.

4 So I think to the extent that 5 Wellpoint, et cetera has a significant book of 6 business in Medicaid, they will be interested 7 in commenting on this, if nothing else for the 8 quote, "burden" end quote, that this will 9 place on their plans. 10 In fact, the core, certainly

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

18 CO-CHAIR WEISS: And I think it's 19 also worth pointing out that since it's 20 inception, NQF has made it a point of 21 including the payers both private and public 22 at the table and at all levels of activity 1 within the organization.

2	So, the actual ultimate debate and
3	approval process will include input from
4	people who represent at very high levels, the
5	provider, community, the research community,
6	the consumer community, but also the payer
7	community. So there will be efforts made to
8	reach out to them.
9	DR. WINKLER: One of our eight
10	membership councils is on health plans and it
11	has, I don't even know the number, but it's at
12	least a dozen of the large, and certainly the
13	large ones.
14	And the reason I know that is I'm
15	just winding up our project on clinically
16	enriched administrative data that is very much
17	something we were focused in on and heard from
18	the regularly.
19	So, they certainly know about NQF
20	and to the degree we can, you know, put this
21	one in front of them we'll do that.
22	DR. BURSTIN: Just one other

1 thought, a lot of the private plans really are 2 very responsive to the large purchasers of health care who are very integrally related to 3 There's a large coalition between the 4 NOF. 5 consumers and the purchaser groups, the consumer purchaser disclosure project who 6 7 routinely come together to look at these issues. 8

9 DR. ZIMA: I had a question. 10 How's the collaboration with NIH going? Ι think just to follow up with Dr. Lieberthal's 11 question earlier about the validity of the 12 13 outcomes measures. Is there much discussion there with NIH as far as putting this on the 14 agenda for more federal research money? 15 CO-CHAIR HOMER: 16 I can answer that 17 in part. I mean I think there are a couple of things. I mean obviously most of this work, 18 as you know, most of the work that NQF kinds 19 20 of measures we're looking at not only have to be conceptually correct and not only have to 21 be reliable and valid, but then actually have 22

1 to be applied in the field.

So that tends to be some distance 2 between NIH and I mean usually running through 3 4 AHRO and/or private foundations. So my sense 5 is there's not a direct linear relationship, there may be special areas like the National 6 7 Children's Study. And again there was a lot of work 8 9 to try to convince the National Children's 10 Study to include some child health -- some health services measures in there work and I'm 11 12 not actually sure where that came up, came 13 out. So, I mean the other thing that I 14 think is included to some extent in some of 15 our reports, it's when there are gaps, we like 16 to feed that up often to AHRQ which then in 17 theory will feed that up to NIH about gaps in 18 availability of data, knowledge, measures. 19 20 So I think it's more a multi-step connection to NIH than a direct broad channel. 21 22 But NIH is a member DR. WINKLER:

of NQF and do they still have a seat on the 1 2 board? Yes, that's what I thought. Just wanted to be sure I wasn't out of date. 3 4 So, NIH is definitely a member and 5 active, you know, leader, partner, member within the organization so it's not -- there 6 7 is a connection for sure. But I would agree with Charlie for 8 9 the most part, we tend to be a post-research effort and so a lot of their work may feed 10 11 into things that ultimately we do, but usually they're a little bit prior to the work that we 12 13 get into. 14 CO-CHAIR HOMER: I mean just building on this a little bit, Marina touched 15 on this briefly, one of the things that 16 happened as a result of the advocacy that 17 Marina led in the -- for the CHIPRA 18 legislation was the creation of a new program 19 20 to develop pediatric measures, broadly. 21 And that measurement program is 22 about to be launched, actually, we just

yesterday got an announcement from AHRQ, that, 1 you know, watch this space come December 2 they're going to be issuing an RFP for people 3 who are interested. 4 5 So again, that's where I see the outcome of this group to the extent that we 6 7 identified gaps in measures that will require development, which I'm sure we will. 8 9 We want to feed into that process 10 so that it's either specified in the next 11 round of our AHRQs language of RFP saying these areas were specifically identified. 12 So 13 I think those are the likely receptor sites for this kind of work. 14 CO-CHAIR WEISS: Charlie's very 15 kind in saying I led it, I didn't, it was a 16 collaborative effort, but I was certainly 17 deeply engaged and happy to be so. I just 18 really think it's worth paying attention to 19 20 the fact that a whole purpose of NQF from its very inception has been to drive towards 21 22 consensus around measures that are in fact

1 ready for prime time.

2	And what's really nice about this
3	project and the reason I'm excited about being
4	associated with it is because in being
5	connected to NQF, we have the capacity not
6	only to work our way toward the HHS, AHRQ, and
7	CMS related body of activity, but also to use
8	the consensus process through NQF to come to
9	closure with the provider community, with the
10	research community, with the consumer
11	community and of course with the payers around
12	a set of robust measures.
13	So the probability that we would
14	be able to launch something here that really
15	is working in the field is actually being used
16	is greater than in any project I've been
17	involved with before. So I'm pretty jazzed
18	about this.
19	DR. WINKLER: Well I have a few
20	more kind of just points in terms of the roles
21	of the steering committee just that I went
22	over briefly just to be sure I didn't forget

any. So like I say, find out exactly what you 1 2 volunteered for. I think for the most part this one 3 I've gone over them and we don't want to 4 5 minimize any one of these steps, but evaluating the measures will be a relatively 6 7 intense exercise or activity depending on the number of measures we have and making those 8 9 recommendations. 10 We will have an in person meeting of this group again in April and at that 11 meeting is when we will be doing the 12 13 evaluations and making those recommendation. Now depending on how many measures 14 we get, like I say if we get six, 60, we may 15 need to have a few preliminary conference 16 calls to kind of get ourselves organized 17 around it. So we're leaving that open-ended 18

19 until we understand exactly what the amount of 20 work it is we have to organize for.

21 So be patient with us we'll let 22 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.

7 CO-CHAIR HOMER: Reva, this will probably come up in the afternoon 8 9 conversation, but maybe to wet our appetite 10 for it, I mean if you look at the previous work, either the other 12 outcome committees 11 you have other than this one, and all the 12 13 previous work of NQF, you could slice every single one of them and say for infectious 14 disease. 15

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.

4 But I mean have we thought, I mean 5 because really, this is one of the issues that those of us in child health get sometimes 6 7 frustrated about where with the adult side you have something on each specific condition and 8 9 organ and in pediatrics there's one when in fact children have all the same number of 10 organs that adults do and then they also 11 12 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

7 do with measure development out there focus.
8 There's just a lot more focus developing being
9 done by organizations that don't feel they
10 have competency in pediatric issues is the way
11 I've heard it placed.

We don't have pediatricians, so we 12 13 don't know how to do that. So I think there are some of the limitations we have 14 experienced, so if you want to help try and 15 bring those in, bridge that, help us figure 16 out how to get rid of the dark lines between 17 kids and everyone else and, you know, where 18 should it blend. 19 20 That's why -- I think this is a challenging way to think about it and how best 21

22 is one of the reasons you're here.

1 CO-CHAIR HOMER: Kathy? 2 DR. JENKINS: And Charlie just to make the point because I think there's a rich 3 opportunity there, it might be equally 4 5 important to say which ones are not relevant in kids and make that an explicit line as 6 7 well. Because again in my recipient role 8 9 a lot of the measures, as people have looked 10 for endorsed measures, have simply been applied in kids and especially when you get 11 into the high stakes measurement often there's 12 13 issues of risk adjustment, small sample sizes, things that are left out of the definition 14 that are being imposed. 15 So, vetting all of that would be 16 potentially extraordinarily important in both 17 18 directions. Kathy mentioned 19 MS. PARTRIDGE: 20 sample size and that might be a way we might find ourselves sorting these down the road. 21 22 Certain conditions are not going to occur very

1	often and depending on what you're measuring
2	whether you're looking at a health plan or
3	clinic or a particular practice, it would make
4	no they would never implement it because
5	they wouldn't have they wouldn't be likely
6	to have the case.
7	So that doesn't mean we shouldn't
8	endorse it, it just means that you might find
9	that the adoption rate would be pretty
10	limited.
11	CO-CHAIR HOMER: Good. Yes,
12	Helen.
13	DR. BURSTIN: Yes, just one more
14	thought. I mean again, a process going
15	forward, we would also be very happy to bring
16	to this committee everything that's going
17	through the other two committees and ask you
18	to look at it through the lens of which of
19	these are actually applicable to kids.
20	I mean one of things we've
20 21	I mean one of things we've discovered at times is we look at a measure

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 4 5 think, if we bring it to you and we'll try to organize that process if you could give us 6 7 feedback on which of those would be applicable, that would be really useful. 8 It's 9 as much as we can harmonize it so that it's 10 one measure applicable to both, obviously that would be best of all. 11 12 CO-CHAIR WEISS: And going back to 13 a point that Reva mentioned earlier. Apparently when the Department of Health and 14 Human Services asked that this project be 15 initiated, the request was framed in the 16 context of the 20 top conditions for Medicare 17 patients. 18 19 And it just occurred to me that 20 maybe we ought to ask for the same bit of information. And I would cut it at least two 21

22

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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 --

10 CO-CHAIR WEISS: I don't know that 11 this would be ultimately the way we would go, but I'm sure it would be interesting to know. 12 13 MS. PARTRIDGE: No, but I think we -- and it will vary tremendously by state as 14 well, I suspect. There will be some very 15 common and then you'll see there may be for 16 others, there may be certain -- more frequent 17 then you would expect. 18 19 I mean I don't, for example, I

20 don't imagine a lot of sickle cell shows up in 21 Idaho.

22

DR. SCHWALENSTOCKER: Just I

wonder if you could say just a little bit more 1 2 about the HHS or CMS that overall charge for this program, is that for measures that will 3 be used for say the hospital RK2PU Program 4 5 ***12:19:38, I love that acronym or PQRI, is there more information you have about the 6 7 intended use of the measures or kind of the origin of the project? 8 9 DR. WINKLER: Helen probably 10 better than that. I mean, I'm not aware of anything that specific just to be used in 11 12 their programs. And so you can kind of 13 extrapolate, but Helen may have additional information. 14 DR. BURSTIN: I mean there's 15 16 clearly been an interest in trying to expand their base of outcomes based measures not 17 surprisingly moving away from some of the more 18 19 process measures to more outcomes. There's not, as I know any, immediate plans to say, 20 21 okay, we have these measures let's put them 22 into a program.

1	But as you know, the measures we
2	put forward can be used in that manner, so
3	nothing clear there other than the fact that
4	there's a strong interest in getting these
5	measures out there in a way that aren't
6	potential for future use.
7	But again, their initial interest
8	was okay, here's the top 20 Medicare
9	conditions and we said, okay that's a little
10	limiting, could we add children and could we
11	at least add mental health as a starting
12	point.
12 13	point. DR. MCINERNY: I don't know
	-
13	DR. MCINERNY: I don't know
13 14	DR. MCINERNY: I don't know whether people have thought about going back
13 14 15	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
13 14 15 16	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
13 14 15 16 17	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
13 14 15 16 17 18	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
13 14 15 16 17 18 19	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

1 quite awhile ago.

I think they were, by today's 2 standards, they're probably pretty crude and -3 4 And I think 5 CO-CHAIR HOMER: 6 they're mainly processed aren't they, of 7 whether things were done in offices, that shouldn't have been done. 8 9 DR. MCINERNY: Yes, I think you're 10 right, and I don't know how many of them were outcomes, but I just wondered because there 11 may be a few that we could look at and see if 12 13 make sense and then probably would need to be developed better than they were back then. 14 CO-CHAIR HOMER: And again one of 15 -- that kind of thing, one of those that 16 informs our thinking about this, but again 17 it's up to the steward or the owner of the 18 measure will then have to decide whether 19 20 they're willing to submit it and tell us 21 basically all -- they do have to tell us all 22 the specifications as well, which some may not 1 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 8 9 look good and have been used, for example, in 10 a research study and are well validated, but have never been applied in sort of a clinical 11 12 either accountability or improvement process. 13 So that's going to be some of the filtering 14 that will happen once we start going through 15 the process.

This is Jane. 16 MS. PERKINS: In terms of the top 20 conditions that children 17 experience, if there could, I don't know 18 whether this exists, but if there could also 19 20 be that top 20 list for children who are --21 who typically I guess suffer from health 22 disparities, does that kind of thing exist?

I know that for African American 1 2 populations often things like that do, but --CO-CHAIR HOMER: I mean we could 3 certainly look at things like MEPS data, 4 5 National Survey of Child Health Data, certainly those are available to be stratified 6 7 by race and by in some cases insurance for MEPS so we'd be able to get that kind of data. 8 DR. SCHWALENSTOCKER: 9 T want to 10 say that every year in ambulatory pediatrics isn't there a report on the top conditions in 11 12 outpatient and inpatient settings? I can't 13 remember who the authors generally are. CO-CHAIR HOMER: 14 Yes. That's usually Lisa and Denise Daugherty are usually 15 the authors of that and I mentioned it to 16 Helen. 17 18 DR. SCHWALENSTOCKER: Right. But with that, my recollection is that those top 19 20 conditions vary quite a bit depending on the 21 age subgroup. So in adolescents you're going 22 to see very different top conditions than in

1 very young children.

2	CO-CHAIR HOMER: Sure. I mean
3	adolescent the most common reason and the most
4	common costs for adolescents is childbirth, so
5	absolutely clear and second is psychiatric
6	disease and third is trauma.
7	So I mean it is or I might have
8	the trauma and psychiatric disease switched,
9	but I know that childbirth is leading. So,
10	clearly and clearly different at the younger
11	age where, you know, again, childbirth for the
12	baby and then the cost of neonatal care and
13	variety of congenital conditions. So, yes
14	that's a great point.
15	DR. LIEBERTHAL: For acute
16	conditions, those reports on the top 20
17	include things like acute otitis media, lower
18	respiratory tract infection and having been
19	involved with the developing guidelines in
20	those areas in looking at those guidelines for
21	potential writing of measures, it's
22	extraordinarily difficult to write process

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1
     measures let alone outcome measures.
                 DR. WINKLER: Anything else
 2
     because I'm at a logical stopping place and
 3
     we're lunch.
 4
 5
                 CO-CHAIR WEISS: Have people take
     a break and pick up their food and do we want
 6
 7
     to continue working during lunch or shall we
     take a little break?
 8
 9
                 CO-CHAIR HOMER: No, let's say --
10
                 CO-CHAIR WEISS: All right, let's
     take a break then.
11
                 MS. PERKINS: Should I call back
12
13
     into this same number then at a set time?
                 CO-CHAIR HOMER: Yes.
14
                 DR. WINKLER: Actually just stay
15
     on is preferable.
16
                 CO-CHAIR WEISS: Or just stay on.
17
                 MS. PERKINS: Okay. I can just
18
19
     stay on.
20
                 CO-CHAIR WEISS: Put it on mute
     and all that.
21
22
                 MS. PERKINS: Yes, okay.
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		Page 1	L51
1	CO-CHAIR HOMER: Very good.		
2	(Whereupon, the foregoing matter		
3	went off the record at 12:25 p.m.		
4	and went back on the record at		
5	1:17 p.m.)		
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21			
22			

1	A-F-T-E-R-N-O-O-N S-E-S-S-I-O-N
2	1:17 p.m.
3	CO-CHAIR HOMER: I hope you had an
4	enjoyable and productive lunch. Looking at
5	the agenda it says Orientation to Project and
6	Role of the Steering Committee, but I think
7	we've done that.
8	DR. WINKLER: We've done part of
9	it.
10	CO-CHAIR HOMER: Okay. So would
11	you like to finish that part of it?
12	DR. WINKLER: Yes, that's the part
13	I wanted to just finish. We had talked about
14	the role of the steering committee and I
15	mentioned that we would be doing measure
16	evaluations by standard criteria. So I just
17	wanted to give you a bit of an overview, we're
18	going to talk in a little more detail about it
19	tomorrow.
20	But it may help you when we're
21	starting to ask, you know, what kind of
22	measures might be out there realizing we need

-- they would all have to be evaluated against 1 these criteria. So it's important to have a 2 sense of what they are. 3 And just historically, NQF has 4 5 always had criteria, they've always had been four major criteria which we'll talk about. 6 7 But through the years as things have evolved, I think it was about a year ago, 8 9 August of 2008 it was a sense that a lot of 10 measures that perhaps weren't as robust as we might like where being endorsed and there was 11 12 a need to try and raise the bar a little bit. 13 And so, the criteria was reviewed 14 by the CSAC and revised a bit. And so we're talking about the revisions. And so -- and 15 the whole point of that revision effort was to 16 clarify, strengthen and recommend changes in 17 order to do a couple of things. 18 We do want to link them to the 19 20 national priorities. So to the degree that 21 they do have that linkage to the NPP 22 priorities and goals we want to highlight

those and also to higher level performance 1 We really want to raise the bar. 2 measures. So realize that if you worked with 3 4 us in the past, in the distant past we are 5 trying to do more. So that perhaps measures that we may have endorsed five years ago would 6 7 not meet the criteria today. So greater measure harmonization. 8 9 We've actually gotten to the point that if the 10 measures aren't harmonized, we won't push them forward for endorsement. It tends to be a 11 12 great incentive to get the harmonization done 13 with folks. And we've had to be fairly pointed in the need to get harmonization done. 14 So it isn't, you know, I think 15 there's a lot more work that can be done in 16 that area and it's always a fine line because 17 we are dealing with someone else's 18 intellectual property. But by the same token, 19 the benefits of harmonization are just so 20 21 obvious that it is a significant priority for 22 us.

1	Greater emphasis on outcome
2	measures. That's why you're here. And for
3	process measures a tighter outcomes process
4	link, which was real important. You know,
5	what is the evidence that they're that this
б	process measure is linked to an important
7	patient outcome.
8	That will be less of an issue for
9	us because we do have outcome measures, but
10	nonetheless, be aware that those are the
11	questions that stakeholders are asking, you
12	know, why is this important, it's because.
13	Okay, next.
14	So in terms of the changes, the
15	emphasis, we've always had four criteria of
16	important scientific acceptability,
17	feasibility and usability, but a couple things
18	have changed.
19	Importance has morphed into
20	important to measure and report. And this is
21	something that people often get very confused
22	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.

5 So something that may be important 6 doesn't necessarily benefit from an important 7 measure. So -- and this becomes a must pass 8 criteria. And you'll see there are several 9 subcriteria that help define what we mean by 10 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 15 is of the measure properties, it isn't so much 16 the evidence that's actually an importance, 17 but it's like that measure, are the 18 specifications precise, do you have adequate 19 20 definitions, what's the reliability, what's the validity, what's the appropriate risk 21 22 adjustment, you know, the measure itself, is

1 it a good, scientifically grounded.

2	Feasibility, again how easy will
3	this be to implement. What are the issues in
4	implementing, particularly as it comes to data
5	source. And one of the criterias on it if
6	you're not using electronic sources, what's
7	your near term path for, you know, specifying
8	this measure for improved feasibility using
9	health IT.
10	And then usability, greater
11	emphasis on harmonization, usability is you
12	generate information when you do a measure
13	it's the so what factor.
14	Who out there is going to be able
15	to use that information to do something with
16	it, make choices, effect change, understand
17	better, whatever, but is it usable in that
18	fashion. So this is how they have morphed
19	over time. Next one.
20	We also have yes.
21	CO-CHAIR HOMER: May I ask you a
22	question?

1	DR. WINKLER: Sure Charlie.
2	CO-CHAIR HOMER: So on some of the
3	other committees I've been on they have a
4	technical panel that answers that number two
5	question of the scientific validity. Do we
6	have that luxury in this?
7	DR. WINKLER: No, actually given
8	the narrow topic area of child health we will,
9	you know, topic but broad, broad by narrow, we
10	actually don't have any technical advisory
11	panels immediately constituted if there
12	depending on the measures we get, and that's
13	why it's a little bit uncertain going forward.
14	If there were a need to identify
15	some technical advisors that you feel would be
16	necessary to help you, we can do that. But it
17	just, in the work plan in anticipation we
18	don't have that set up. The main steering
19	committee it's looking all the other
20	conditions actually do have several TAPs
21	helping them out.
22	DR. RAO: Just a question. Do we

have anyone from CMS, for example, that can 1 just tell us well you can't measure that, they 2 don't record that or if they could give us 3 quick advice. 4 5 DR. WINKLER: We can always ask 6 that question but realize that CMS is not our 7 only --DR. RAO: Yes, I know. 8 9 DR. WINKLER: Yes. 10 DR. RAO: It's a possibility. 11 CO-CHAIR HOMER: So what you're 12 saying is it's not in the plan now, but if we 13 were to get five measures, I mean we happen to have great strength in cardiology here, but 14 for example there is, and you've already had 15 something on that, but for example were we to 16 get 10 measures that were looking at something 17 like that and they all use different severity 18 of illness categories, we might be able to 19 20 pull in, if we didn't happen to have on this committee --21 22 DR. WINKLER: Right.

1 CO-CHAIR HOMER: -- the technical 2 expertise that we needed? DR. WINKLER: Yes. I think that's 3 4 one of the problems in project planning is 5 really without knowing what measures we have. So I think we have to have -- leave it a 6 7 little bit open ended to see what we're actually going to be looking at before we 8 9 know. 10 But we certainly can bring that 11 additional expertise in if it's your directions. Couple of things just so that you 12 13 know about the conditions for a measure to be evaluated by NOF and the measure is either in 14 the public domain or we have an intellectual 15 16 property agreement signed by the measure steward. 17 18 The measures have -- are not -can't be black box measures. We can't hide 19 20 significant aspects of the measures, they have to be open source, they have to be made 21 available. 22

1 You have to be able to see all of 2 the elements, all of the details, you know, all the codes, all the exclusions, all the 3 equations, whatever it is, you need to see it 4 5 all. And so that's important. Each measure, there might be a lot 6 7 of public domain measures out there, but if they don't have an owner that takes 8 9 responsibility for them that will act as a 10 steward going forward, then we're not able to deal with it because we need a relationship 11 12 with the measure steward going forward. 13 Because measures need to periodically be updated, revised, we have 14 questions, someone has to take that 15 16 responsibility. As we've talked about earlier, the intended use must include both 17 the public reporting, it's the accountability 18 part that is NQFs focus as well as quality 19 20 improvement. 21 So the basic, you know, lower 22 level internal QI kind of measures are really

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

And then we do ask one of the 3 criteria that we have is that the information 4 5 be complete. We now use an electronic 6 submission process that helps us manage just 7 a large amount of data and it helps us create the output for you to look at on your 8 9 evaluation form. 10 But if half of it's left blank, 11 there's very little for you to work with or any of us to work with. And we're really 12 13 trying to minimize extraneous attachments and extra documents that we have to, you know, go 14 through. 15 16 So to give you a standardized format so you always know where the 17 information about validity and reliability is 18 in your standard evaluation form that we'll 19 20 give you, we do require that. So these are just the kind of 21 22 conditions we put up front on the measure

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

6 We can't deal with that anymore, 7 things have got to be a lot more detailed and 8 organized and complete in terms of 9 information. So, just the last thing in terms 10 of timeline, where we're going for this whole 11 group.

12 You're here at the first meeting, 13 we're going to be doing the call for measures right after the first of the year, it's a 30 14 day call for measures. We want -- we'll need 15 16 your help to try and be sure we get the word out so that we can keep to that timeline 17 because we actually need all the measures in 18 our hands, you know, just as soon as that 19 20 closes in 30 days.

21 Because, like I say, if there are 22 six, you know, we can relax a little bit, if

there are 60, we're going to have some 1 2 interesting issues with volume. Our second meeting is -- will be 3 in April, which indeed is the meeting we will 4 5 ask you to be doing the evaluation and recommendation of those measures. And Melissa 6 7 will organize asking you all when, you know, what the best date, two days for a meeting in 8 9 April will be. And as I said, if indeed we get 60 10 measures and we have to break them down and do 11 something and do a couple lead in conference 12 calls we'll do that. 13 We will let you know as soon as we 14 know how many measures there actually will be, 15 but it will be at the end of the 30 day period 16 once the submission closes, we'll check the 17 spreadsheet and count them up and see how many 18 we've got and see how they spread in terms of 19 20 topic areas and if there's some natural divisions and breakouts. 21 22 And then, then we'll take a look

to see if there's additional expertise or 1 2 whatever that we may need. So we will certainly be back with you once that closes to 3 4 let you know the work that we have ahead. So 5 is there any questions, kind on -- these are just some real basic how NQF operates issues 6 7 so that you at least have a general introduction. Kathy? 8 9 DR. JENKINS: I just -- what 10 happens next then? Because I have a feeling 11 that a lot of these measures, you know, we're 12 going to have to use what's available now and 13 some of them may be those time limited endorsements and then like how does this go 14 forward and stay together with the national 15 16 process and AHRO and others. The HHS contract 17 DR. WINKLER: that we're working under actually is a four 18 year, potentially four years of work, and 19 20 we're already working on next year's work plan and the following years work plan and since 21 22 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

9 likely to have another avenue of looking for 10 outcome measures to fill those gaps.

8

them, then, you know, in a year or two we are

11 That really is one of the goals 12 from the Agency in terms of doing this work 13 and outcomes is just a huge priority. So this 14 is just sort of a first effort and then the 15 second wave will be another chance to make it 16 better, if you will.

17 Any other questions? Jane did you 18 have a question or anything, out there in the 19 sky?

20 MS. PERKINS: No. I'm just sort 21 of, you said 60 so many times I'm starting to 22 freak out every time I hear you say something.

1	DR. WINKLER: Yes. I don't mean
2	to do that to scare you, I just am trying to
3	be extreme.
4	DR. CLARKE: I have kind of a
5	comment.
6	CO-CHAIR HOMER: David had a
7	question, go ahead.
8	DR. CLARKE: I have kin of a
9	comment and a question. It seems to me that
10	moving forward the framework that we need to
11	end up with has got to be some kind of a
12	hierarchical relationship because other than
13	that, it's going to be very difficult to
14	integrate it into the various databases and so
15	forth so that it can be used easily.
16	And I don't know that it really
17	matters whether we, you know, start with the
18	hierarchical groups and then, you know, sort
19	of use that framework to recruit measurements
20	or whether we just collect all the
21	measurements and then form the groups later or
22	maybe some combination of both. Can you

1 comment on that?

2 DR. WINKLER: What we're going to 3 do this afternoon is we have a couple of 4 things to just put on the table for your 5 consideration and then I'd like you all to 6 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 14 organization of your discussion and have a 15 revisit of it tomorrow morning so we can kind 16 of see what did you get, how might we put it 17 together, do a little bit of thinking on the 18 part of the staff tonight, to help see if we 19 20 can get the beginnings of that organizational 21 structure.

22

Quite possibly it will be a first

pass and there will be discussion tomorrow 1 2 morning which then we can give you the second draft by e-mail and we can do one of those 3 sorts of things, so over the next couple of 4 5 weeks we can kind of build this. 6 But this is the beginning while 7 we're getting to know each other and we're here, we can have an opportunity to do this 8 9 kind of collective thinking and see if we can 10 figure out what this picture should look like. And so however you think it may 11 work best for you, you know, we'll try and do 12 13 whatever we can to support it, okay? 14 Okay. I've just got a couple of things, as I mentioned we wanted to offer just 15 a couple of thoughts on outcomes to help you 16 set the scope, and that's essentially what 17 we're doing. 18 With any project, we have to know 19 what the boundaries, you know, what's in, 20 what's out because otherwise if the entire 21 22 universe is in, it will drive you crazy. So

we have to know exactly what box are we going 1 2 to try and live in. And it's not necessarily a slam 3 dunk decision, so we do want to give you the 4 5 chance to consider some ways of looking at this. 6 7 Just, we are dealing with outcomes, so keep that in mind. And going 8 9 back to the granddaddy of them all, you know, the definition of an outcome measure and 10 Donabedian's classic construct is referring to 11 changes both desirable and undesirable in 12 13 individuals and populations that are attributed to health care. 14 Okay? So that's where we're at. 15 That's kind of what we're talking about. 16 Does anybody have any questions or comments on that 17 as a definition? Ellen? 18 19 DR. SCHWALENSTOCKER: So being 20 sort of a Donabedian devotee, I've had this sort of nagging concern today about, and I'm 21 22 respectful of focusing on outcomes and

recognizing that that's part of our scope, but 1 2 it seems to me -- or that is our scope, it seems to me that process outcomes link is 3 4 going to be very important for us. 5 I think Reva, you mentioned 6 earlier that process outcome link is 7 considered important when considering process measures, but it seems to me we've got to 8 9 think that way in terms of outcomes measures 10 or how are we going to link them to improving -- link them to specific interventions, if you 11 will, to improve care? 12 13 DR. JENKINS: Ellen, do you mean they need to be actionable or you need to know 14 what the actions are that influence the 15 outcomes that can be improved upon is that 16 17 what you mean or? DR. SCHWALENSTOCKER: Yes. 18 That's what I mean. Thanks. 19 DR. WINKLER: I'm sure that will 20 21 become a discussion point when you look at 22 each of the various measures. But to the

1 degree that evidence-base -- there is an
2 evidence-base that can answer that question,
3 it is one of the questions in the measure
4 submission.
5 So that information is there.

6 It's a little bit more tenuous on an outcome 7 measure than it is on a process linking it to 8 an outcome. So we'll have to evaluate each 9 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.

1	CO-CHAIR HOMER: It always comes
2	up for immunization. I think hospitalization
3	as a quote, "outcome measure" is another one
4	that's, you know, on the fence I would say.
5	And we're just going to have to discuss that.
6	DR. RAO: Just a comment, in terms
7	of immunizations for example, isn't a process
8	outcome just being offered immunization or
9	offering immunization for the parent rather
10	than actually receiving it just because if
11	they refuse then you still followed the
12	process per se.
12 13	process per se. DR. WINKLER: I think that there's
13	DR. WINKLER: I think that there's
13 14	DR. WINKLER: I think that there's interest actually in knowing all of those
13 14 15	DR. WINKLER: I think that there's interest actually in knowing all of those different elements of it, but actually the
13 14 15 16	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
13 14 15 16 17	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.
13 14 15 16 17 18	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,
13 14 15 16 17 18 19	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

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.

9 DR. LIEBERTHAL: When we talk 10 about process measures and outcome measures we 11 also have to look at who are we measuring. 12 When you're talking about a health care 13 organization, the measuring the outcomes for 14 their population is relatively easy to do and 15 meaningful.

16 The problem you have when you're 17 evaluating providers is that they do not 18 directly control the outcomes when you're 19 talking about chronic disease. For example, 20 in asthma a patient may see multiple providers 21 plus socioeconomic adherence many, many other 22 things contribute to the outcomes that are 1 unrelated to what the provider did.

And it becomes a real difficult 2 problem when you try to attribute outcomes to 3 individual providers. 4 5 DR. WINKLER: In this particular 6 case we are not designating the level of 7 analysis for outcome measures per se and many of these measures, for a lot of technical 8 9 reasons, but for a lot of philosophical 10 reasons may only be applicable at larger 11 levels of analysis such as at a hospital level, at a plan level, at a large group 12 13 level. One is just sheer numbers, but I 14 think each measure would have to be evaluated 15 on a -- as an individual at one, the measure 16 developer is going to designate what levels of 17 analysis they believe it's suitable for and 18 then that will be part of your evaluation as 19 to what levels of analysis you believe that to 20 21 be that they presented the case for or not.

So it's conceivable that among the

22

list of outcome measures that you recommend, 1 some will be at certain levels and some -- and 2 none of them may be at individual provider 3 4 levels, but may be at larger levels of 5 aggregation and analysis, and that's perfectly fine. 6 7 CO-CHAIR HOMER: The only restriction that we're proposing here is the 8 9 one Donabedian talks about, that is that we 10 can reasonably attribute these to health care. DR. WINKLER: Yes. 11 12 MS. PERKINS: I actually -- I have 13 a question about that. 14 CO-CHAIR HOMER: Yes, it's a good -- go ahead. 15 MS. PERKINS: Yes, what does it 16 Does it include education, does it 17 mean? include things like personal care services 18 that children with chronic needs really do use 19 20 and need? 21 CO-CHAIR HOMER: Well for example, 22 so I think on the table for discussion, so

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

7 So in that context it's probably 8 fair for us to at least at a first pass say to 9 put on the table whether we want an index of 10 academic achievement as a potential outcome 11 measure.

12 I'm not saying on or not, but I 13 mean I think that's a potential outcome measure that we should at least think about is 14 that in or out of scope and then I think we as 15 16 a group probably would want to wrestle with, well what proportion of variance, for example, 17 in a population outcome measures could be 18 achieving at the health care and would we be 19 20 willing to hold any health care organization accountable for that outcome. 21

22

And if we would say yes, then, you

know, we probably should at least be within 1 our scope. So that would be my guess. But as 2 opposed to, well again we're not really 3 looking at processes. 4 5 I mean if we -- I don't think we 6 should be looking at processes within schools 7 or, you know, whether there's a school lunch program or not even though that may have a 8 9 health outcome that we care about, you know, 10 we're looking at outcomes. But I think to me the critical 11 12 question is can the outcome or are we or would 13 somebody be willing to hold a health care delivery organization at some level between 14 provider and Kaiser, you know, probably at 15 that range accountable for an outcome. 16 DR. PERSAUD: Well I think what 17 that raises is really that one outcome isn't 18 depending on just one thing, it's a matter of 19 attributable cost. 20 21 Right. CO-CHAIR HOMER: 22 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.

5 For me in prevention medicine, I 6 think we should start to entertain those 7 discussions about academic achievement because 8 I think there is a theoretical relationship 9 between the health care provider than academic 10 achievement.

11 It's just that the contribution is 12 varied and maybe even variable across systems 13 and maybe those are the kinds of things that 14 we should start to address.

15 CO-CHAIR HOMER: And again, as the 16 materials, we said when we start looking at 17 outcome measures there's an assumption that we will need to include, risk adjustment for 18 different categories of risk and/or 19 20 stratification which is the approach that NQF uses for dealing with socioeconomic and racial 21 22 disparities rather than risk adjustment.

1 So that's -- that, for example, 2 race or a class is a stronger determinant of 3 outcome or a major determinant of some of 4 these broad outcomes is kind of accepted and 5 is a given and not a reason that we shouldn't 6 include an outcome that has those as major 7 determinants.

8 We would just need to see when we 9 see a measure come in, the measure proposer 10 would have to tell us how the measure either 11 adjusts for that or proposes to collect data 12 and stratify that depending on what the risk 13 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 1 2 the scope of outcomes measures? 3 DR. WINKLER: It's more your second question, should we. 4 5 CO-CHAIR HOMER: Okay. Kathy? Charlie when you 6 DR. JENKINS: 7 just said that there had to be attributions to a health care organization or entity I guess 8 9 I got a little confused because I thought that 10 there could be both public health perspective, population based health outcomes that for 11 example the state of Massachusetts could fill 12 13 ownership of or an accountable role to play that could potentially be something within the 14 boundaries of your question before about 15 attribution that we could consider. 16 Is that 17 not correct? CO-CHAIR HOMER: So as that 18 evolved, I've been on different committees and 19 20 the sense in the past I've been on was if it

was that the health care system, health care 22 delivery system had to have a potential impact

21

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1 on that.

2 DR. JENKINS: Well in some ways 3 you could say that a state is a provider of 4 health care in a variety of ways, certainly as 5 a payer, as an insurer through their Medicare 6 programs.

7 So, you know, I don't think it's too big of a stretch and in fact one of the 8 9 things Bonnie is going to propose is how do 10 we, you know, look at these two together from the more traditional way that NQF has always 11 looked at, you know, specific levels of 12 13 analysis versus, you know, we do care about the population and the contributions to the 14 larger -- how do we make that jump? 15 Where are they connected? 16 What are those connections? And this, particularly 17 around children seems to be a good project to 18 explore some of that to figure out how we 19 20 might begin to think that through. And so that's why Bonnie's going to talk a little bit 21 22 about some of these things together.

1 I think a lot of these are a 2 little bit open and you're input is helping us try and figure out maybe the best way to go 3 So it's not as if there's some 4 forward. 5 absolutes here, but I think Charlie's right. 6 I don't think we want to range so 7 far out there that we're worrying about what's going on in the schools too much, you know, 8 9 and hold the school accountable as opposed to 10 need to be something that's a little more health care oriented to keep it at least 11 within a reasonable kind of purview for us to 12 deal with. 13 14 CO-CHAIR HOMER: Lee? 15 MS. PARTRIDGE: Charlie you're raising the schools of course is a very 16 significant departure from what we normally do 17 around an NQF steering committee table. 18 And I was thinking, we do talk about missed school 19 days, which is often tied, particularly to 20 control of certain chronic conditions. 21 22 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.

5 DR. WINKLER: Let me do something, 6 go ahead two slides. This is a list of the 7 types of outcome measures that actually we've 8 used in the HHS proposal, but I also put to 9 the main steering committee who are doing, you 10 know, all the 20 conditions things and asked 11 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.

8 One is patient function or 9 symptoms or sort of the health related quality 10 of life. When you talk about function, to me 11 a measure of function might be missed days of 12 work, missed days of school, able to do your 13 usual activities, whatever.

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

16 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.

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1	The third one is patient
2	experience with care or some assessment of
3	patient knowledge of understanding of their
4	health condition, health risk status,
5	motivation, kind of those patient thinking
6	kinds of things. Outcome measures?
7	CO-CHAIR HOMER: I would have a
8	split vote on that to tell you the truth.
9	DR. WINKLER: You'd have split
10	vote?
11	CO-CHAIR HOMER: Yes, I think you
12	could
13	DR. WINKLER: What do you want to
14	split?
15	CO-CHAIR HOMER: I would say
16	experience of care is an outcome measure, it's
17	one of the core dimensions of quality and
18	knowledge per se, is not in my view an outcome
19	because knowledge is not really knowledge
20	is a beautiful thing, but it doesn't relate to
21	either health related behaviors or health
22	outcomes. So I personally would exclude

1 knowledge.

2	But that's so that's why I said
3	I might be a splitter on that and not
4	consider them all part of the same.
5	DR. LIEBERTHAL: Patient, I don't
6	know, knowledge and understanding and their
7	adherence is a function of a system that
8	provides the education in a way that the
9	patient can absorb it and understand it, which
10	is not our normal way of interacting with
11	patients.
12	And I think that this is a key
13	outcome when looking at overall health because
14	if the patient, if we have not conveyed the
15	knowledge at the level that the patient can
16	understand it and effect their behavior and
17	I'm not quite sure the best way to do that,
18	the outcomes may be disconnected from the
19	health care provided.
20	DR. CLARKE: Well, it seems to me
21	that the outcome, I agree patient experience
22	with care which is patient satisfaction is an

outcome. But the outcome is the behavior and 1 2 the adherence to care and the acceptance of the prescribed care and the actual follow 3 4 through, that's the outcome. 5 I don't think you can measure accurate the knowledge, understanding, 6 7 motivation and all that stuff. DR. MCINERNY: Well I think now 8 9 that we have motivational intervention 10 available, we probably could significantly improve outcomes for things like smoking 11 cessation and prevention or treatment of 12 13 obesity; however, I don't know if that link has been thoroughly studied. 14 15 But it seems to me that the good old loose weight because I told you to or stop 16 smoking because I told you to clearly doesn't 17 work. And on the other hand if one uses 18 motivational intervention that -- I've seen 19 20 some indication that that probably is far more 21 likely to improve outcomes in the long run. 22 But that's going to be asking a lot of the

1 system.

2	DR. PERSAUD: I think that bullet
3	three is probably a continuum of processes
4	that lead up to an outcome and we've got too
5	many things probably lumped together.
6	I would throw in that probably the
7	big buzz word in all motivation now is
8	readiness for change in case you want to add
9	anything in there that's going to give you an
10	idea of where the person is moving between
11	understanding to doing something, I think
12	readiness for change is in there.
13	So I would propose that maybe
14	
	three just be separated out or we need to just
15	three just be separated out or we need to just understand. I think three is a continuum that
15	understand. I think three is a continuum that
15 16	understand. I think three is a continuum that some of those are process, some of those are
15 16 17	understand. I think three is a continuum that some of those are process, some of those are intermediate and some are outcome.
15 16 17 18	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
15 16 17 18 19	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
15 16 17 18 19 20	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

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.

7 DR. ZIMA: I do agree we have to unbundle this. And one resource is Barbara 8 9 Rimer I-M-E-R, she has a textbook on health 10 behavior and health provider education. And what she taught me through that book, and it's 11 in the fourth edition now, is that there's 12 three decades of work on social sciences. 13

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.

21 CO-CHAIR HOMER: So what I heard22 in that discussion was I think general

recognition that experience is an outcome and 1 some sense that the rest of them are on a 2 continuum towards leading to outcomes and 3 which of those we actually include. 4 5 A, we need a better categorization of them and this is a little less 6 7 sophisticated than it should be. And I think once we have that, I think we would need to 8 9 revisit further whether we consider -- the 10 sense I had was most people think these are important steps on the way to behavior change. 11 Whether they should be measured, 12 13 all measured and considered as quote, "outcomes" I think we have not yet come to 14 consensus on. That's what I -- did I capture 15 that? 16 17 DR. WINKLER: Okay. We can try and redraft it based on your input. 18 Because I think some -- because I'm thinking of this 19 20 as being sort of the backbone of this call for 21 measures, you know, we are looking for 22 measures of these types and describe them.

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1	So the degree we can make them as
2	clear and understandable to a broad audience
3	is important. So we'll kind of redraft them
4	and get them back to you for further thinking.
5	The next one is service
6	utilization as a proxy for outcome and under
7	this comes readmissions
8	CO-CHAIR HOMER: Or admissions
9	DR. WINKLER: or admissions for
10	things that perhaps didn't need to happen or
11	ER visits or, you know, those sorts of things.
12	That's what's meant there. Any question about
13	those being outcomes?
14	DR. LIEBERTHAL: Yes, when you use
15	the term service utilization and then relate
16	that to an example is readmissions, I'm not
17	quite sure I understand the wording or how
18	service utilization
19	CO-CHAIR HOMER: for example it
20	would be
21	DR. LIEBERTHAL: Yes, I'm not
22	the terminology doesn't

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1
                 DR. WINKLER: Work for you?
 2
                 DR. LIEBERTHAL: -- work for me.
 3
     I wouldn't have come to readmissions after
     reading that statement.
 4
 5
                 DR. WINKLER: Okay.
 6
                 CO-CHAIR HOMER: So it's not
 7
     question --
                 DR. LIEBERTHAL:
                                  It's not clear.
 8
 9
                 CO-CHAIR HOMER: -- with the
10
     content, it's more the words that are
    described --
11
12
                 DR. LIEBERTHAL: The clear, it
13
     isn't clear to somebody who hasn't seen it
    before.
14
15
                 CO-CHAIR HOMER: But the concept
     though, for example, the potentially
16
    preventable hospitalization for asthma of
17
     something like that would be a kosher -- you
18
     consider that an outcome measure?
19
20
                 DR. LIEBERTHAL:
                                  Yes.
21
                 CO-CHAIR HOMER: Okay. Bonnie.
22
                 DR. ZIMA: There seems to be a lot
```

of emphasis on avoiding of excessive services, 1 but how about dropout? How are you handling 2 that? 3 CO-CHAIR HOMER: So meaning either 4 5 under use --6 DR. ZIMA: Yes. 7 CO-CHAIR HOMER: -- people who are not receiving therapy that they should be 8 9 receiving? 10 DR. ZIMA: Yes. It's certainly a 11 big issue in mental health. I mean the average number of visits for a child in a 12 13 community mental health center is one. 14 DR. WINKLER: These tend to be, you know, the more efficacy kind of measures 15 in terms of in process it's how many of them 16 are doing whatever needs to be done. 17 The related outcome though would be what we'd be 18 looking for. 19 So even if patients drop out, 20 presumably their outcome will suffer as well. 21 22 So that would be captured in the actual

outcome measure for this particular approach. 1 You know, that's the difference between 2 process and outcome measures I think. 3 I think that's 4 CO-CHAIR HOMER: 5 right. So I guess the question, if you had no other data but simply data that said 46 6 7 percent of children didn't complete their course of children in one program compared to 8 9 10 percent in some, you know, would that be 10 sufficient information on outcome to allow you to make a decision that the outcomes are 11 better in one or the other assuming the 12 13 treatment is efficacious? 14 DR. ZIMA: It's interesting because there is a body of literature that 15 shows that mental health care is ineffective 16 in real world treatment settings. 17 18 CO-CHAIR HOMER: Ineffective? Ineffective using 19 DR. ZIMA: 20 either weightless control or children who have 21 dropped out of care. 22 So that would say CO-CHAIR HOMER:

that -- so that would answer your question 1 which is that we couldn't use --2 DR. ZIMA: I don't know. 3 4 CO-CHAIR HOMER: -- outcome --5 DR. ZIMA: It's a murky issue, but 6 I think dropout is a big problem with our 7 child mental health. CO-CHAIR HOMER: So again, one of 8 9 my general principles on sort of quality 10 measures, again, this is more my philosophy maybe not my Chair role, but maybe it is. 11 12 I mean, a quality measure 13 particularly if we're either asking -- we're either holding somebody accountable, which 14 means basically you'll get paid more or less 15 or you'll get a contract or not less 16 ***1:58:57 or you're going to do a quality 17 improvement program which is we would like you 18 to achieve a higher level of performance. 19 20 You have to have a fair degree of confidence that what you're articulating is 21 22 quote, "The right thing to so," I mean the

right thing for the right patient at the right
 time.

3 So if it's a murky area, which will come up I think at our conversations 4 5 repeatedly over the next several months, probably means not ready for prime time. 6 Ι 7 mean not ready for us to endorse as a measure that NQF is going to stand behind and say 8 9 plans or practices or hospitals or providers can and should measure this element. 10 It's a very different framework 11 12 from a research framework. Kathy? 13 DR. JENKINS: I had the same comment as Allan about the wording, but what 14 I read into it was the guestion about whether 15 costs of care could be considered an outcome 16 17 measure and I guess my answer is yes particularly through the lense of efficiency. 18 And if that's not what was meant 19 by the fourth bullet then I think it should be 20 up there somewhere. 21 22 DR. WINKLER: Yes, cost of care is

an outcome measure. I can tell you that just 1 in the weirdness and the way these projects 2 are set up, they actually is the different 3 projects looking at the cost of care elements 4 5 of it. So I think we'll put it there, but 6 7 it won't be what we call for just because by contract it's out of scope not by 8 9 conceptualization it's out. But I don't -- I 10 think putting it there to include it so we know that we're not deliberately excluding it 11 12 from our thinking is appropriate. So thank 13 you Kathy. 14 Any other comments or questions, we move down the list. Okay. The next one is 15 non-morality morbidity related to disease 16 control and treatment. 17 And sort of classic one is, you 18 know, amputation as a result of poor diabetic 19 20 control, you know, serious preventable morbidity or dialysis or something like that 21 22 that on the long term. So I think there are

1 some other ones.

2	And then the next one is health
3	care required adverse event or complication.
4	These are the not so desirable outcomes and
5	then of course mortality.
6	So the question I'll ask you with
7	the wordsmithing and the caveats we've already
8	talked about, this to me seems like it forms -
9	- is going to form the basis for our call for
10	measures that we're looking for measures of
11	all of these types.
12	I think we'll need more, but is
13	there any can you, off the top of your head
14	at this point, think of anything else that's
15	not there? And we're going to have further
16	discussion, but
17	CO-CHAIR HOMER: Development. So
18	I mean to some extent you could put it under
19	your patient function, symptoms, health
20	related quality but again that's sort of
21	DR. WINKLER: You're talking about
22	physical development, right?

1 CO-CHAIR HOMER: I'm talking about 2 physical, cognitive --3 DR. WINKLER: Cognitive, the whole thing, right. 4 5 CO-CHAIR HOMER: -- emotional 6 development. I'm talking about all the 7 dimensions because that's, I mean that's the critical outcome for childhood that's not 8 9 captured well. 10 DR. WINKLER: Does everybody agree 11 that that's particularly especially for children? 12 13 DR. DOCHERTY: I saw that under that patient function, health related quality 14 of life, physical, mental, social, I was 15 looking for that and that's where --16 17 DR. WINKLER: Okay. 18 CO-CHAIR HOMER: Yes, I think that is where it would --19 20 DR. DOCHERTY: -- needs to be more 21 specified. CO-CHAIR HOMER: -- fit. I think 22

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

3 DR. WINKLER: Okay. Works for me. 4 CO-CHAIR WEISS: I like it. If 5 we're finished with that I want to go to that 6 same bullet but with a slightly different 7 item.

8 DR. MCINERNY: Just a comment on 9 what Charlie said, I think, you know, the idea 10 of getting children into early intervention if 11 we do a good screening job for developmental 12 delays is at a -- being in early intervention, 13 is that an outcome, no probably not.

But is it a good proxy for an 14 outcome or do we have to follow them through 15 their early intervention and see if somehow 16 they were ready for kindergarten because of 17 the early intervention because you identified 18 as developmentally delayed too. 19 I have a 20 problem with knowing exactly how you -- where 21 you go with that.

22

CO-CHAIR HOMER: Without answering

the question, I think what we'll have to 1 2 wrestle with is the certainty of the link. I mean really that's a process 3 4 outcome connection that is being in an early 5 intervention program, process that leads to an outcome and it depends on how confident we are 6 7 that that process -- I mean if it was as clear as immunization linked to the other ones, then 8 9 it would be fine. 10 If it weren't, then it's a process 11 measure and maybe a very legitimate process measure that we would want -- that a committee 12 13 that would be looking at, you know, child development process measures would look at. 14 The only caveat I have is whether that counts 15 16 as service utilization as a proxy for an 17 outcome. DR. ZIMA: It's an interesting 18 point because I think that we know that 19 20 detection doesn't necessarily improve access to care. So as we kind of go down this slow, 21 I mean how much would a recommendation of 22

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

CO-CHAIR HOMER: I'd be absolutely 3 4 confident in saying for example, doing a 5 developmental screen is a process measure and 6 not an outcome measure. And even filling out 7 a referral form, the EPS, you know, early intervention program is a process measure and 8 9 not an outcome measure. 10 Whether somebody's enrolled in an 11 early intervention program versus whether they are ready for school at age five, which would 12

13 be a better outcome measure I think is really 14 for us to wrestle with.

DR. RAO: Just thinking about a 15 16 possible, you know, outcome measure that might cross a lot of different boundaries and 17 categories, what about physical fitness if 18 somebody -- I would propose that as an 19 20 outcome, where would that fit in? Is it a functional sort of thing, is it really related 21 22 to health care or --

1 That seems to me if DR. DOCHERTY: 2 we're going to add a bullet on growth and development it seems to fit under that. 3 4 DR. RAO: Yes, as a separate thing 5 under growth and development. 6 DR. DOCHERTY: Yes. Well as part 7 of the growth and development would be physical functioning, you know, appropriate 8 9 levels physical functioning at the age. And 10 I wasn't understanding were people questioning whether or not growth and development could be 11 an outcome at all? 12 13 Because we certainly use that a lot with the chronically ill children. 14 Ιf they've been in the hospital we look at, you 15 know, what kinds of growth and development 16 outcomes are we seeing when they're -- so we 17 use that a lot for the chronically ill. 18 I had a comment about 19 DR. CLARKE: 20 morbidity first and then about mortality. Actually bullets five and six I think are the 21 22 same thing, they're both clinical morbidity.

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1 And what we found when we tried to objectively evaluate morbidity in the large 2 group of cardiac surgery patients that we 3 looked at was that for most adverse events 4 5 that are temporary and reversible length of stay in the hospital serves as a fairly good 6 7 surrogate for measuring that. However, the occasional durable 8

9 adverse event like a neurological injury or 10 heart block or, you know, a few other sort of 11 like permanent dialysis those kinds of things, 12 are very, very difficult to measure because 13 you find that unless you weight them just 14 incredibly heavy, they contribute nothing 15 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.

22

And then as far as mortality and

also morbidity together, I think that in the 1 pediatric arena, this is where some sort of 2 risk or complexity adjustment is vital. 3 Because if were going to make these public, 4 5 it's key by the door ***2:07:45. 6 CO-CHAIR HOMER: Well agreed. And 7 just on my comment earlier, just echoing the NQF standards, the NQF acknowledges that 8 9 outcome measures need to be risk adjusted 10 unless proven otherwise. So, Kathy? 11 DR. JENKINS: The other thing I don't see there is I see patient functioning, 12 13 but I don't see patient and family functioning which in a pediatric context I think probably 14 does deserve to be an outcome measure, whether 15 it's parent satisfaction, family functioning, 16 what -- across the board to kind of -- maybe 17 that's about scope, but I think it needs to be 18 there. 19 20 CO-CHAIR WEISS: Well we probably 21 need to say that about a number of these 22 items, especially for the smaller children.

We're really talking about parental 1

satisfaction rather than talking about toddler 2 satisfaction, for example. 3

I wanted to go to bullet number 4 5 one under the patient function and just say from the perspective from those of us who are 6 7 in the world of advocacy and trying to see to it that things are reimbursable and whatnot 8 9 through various programs be they private or 10 public, one of the things that we run into a lot is the issue of function. 11

12 And the standard that we run up 13 against is that a function is not improving then it cannot be reimbursed. 14 But for children especially it seems to be necessary 15 to stipulate that maintenance of function is 16 important. So I would like to see that there 17 in some way. 18 MS. PERKINS: Also under Medicaid 19

20 you don't have to be improving to be reimbursed for children. 21 22

Jane, could you DR. JENKINS:

1 speak up?

2	MS. PERKINS: I just said also
3	under Medicaid you don't have to be improving
4	to be for there to be a requirement to
5	reimburse. The service just needs to be
6	correcting or ameliorating the problem.
7	CO-CHAIR WEISS: That is
8	absolutely correct and it was moving mountains
9	to get to that place.
10	MS. PERKINS: Yes, no kidding.
11	DR. JENKINS: And along those same
12	lines, and maybe this is already implicit in
13	just naming the overall outcomes like growth
14	and development like Charlie did, but I'm
15	looking for something that I think is much of
16	an issue in kids than in adults, which is
17	attainment of optimal functioning as opposed
18	to an adult's where there's loss of function,
19	that inability to attain what one should have
20	had available.
21	I don't know how exactly to put
22	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 4 5 ties into the IOM report that was e-mailed around last night that sort of defined child 6 7 health in the context of obtaining optimal health and growth. Ellen, did you have a 8 9 comment? 10 DR. SCHWALENSTOCKER: Yes. I'm

thinking of the National Priorities 11 Partnership priority on coordination of care. 12 13 And I'm thinking of things about receiving appropriate follow up and whether that would 14 be a process measure or whether it would be a 15 flip side of service utilization, but I'm 16 wondering if we need something like that in 17 18 there.

19 CO-CHAIR WEISS: Well it certainly 20 would apply in the case of inpatient based 21 screening and identification of disorders or 22 conditions or whatever on which follow up is

1 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.

I mean my gut is 8 CO-CHAIR HOMER: 9 that that's a process and we need to think of 10 what the outcome is that that would be likely to address and it may be very variable 11 depending on what the condition is and it may 12 13 be a satisfaction or experience of care or duplication efficiency measure outcome as for 14 the --15

16 CO-CHAIR WEISS: Well just taking 17 as an example hearing screening in the 18 hospital and the child is identified through 19 the screen as having a deficiency, but that's 20 going to be picked up in the outpatient 21 setting. 22 It's process initially in the

intermediate phase, but then what has to 1 happen and who is the provider held 2

accountable? 3

4 CO-CHAIR HOMER: So seeing as we 5 do a lot of work in that area, the next level 6 of processes was -- I mean the recommendation 7 of course is that they be screened in the newborn they have confirmation by one month 8 9 and you have definitive -- I think one month 10 and definitive diagnosis by six months. I'm 11 sorry or definitive treatment actually started by six months. So --12

13 CO-CHAIR WEISS: So do you wait for treatment then and --14

CO-CHAIR HOMER: So the question 15 is what the outcome -- what's the outcome is 16 that it's done each of those three things as 17 a proxy. We actually had this intense debate 18 at the U.S. Preventive Service Taskforce and 19 20 fortunately we got them to reverse their findings on that. 21 22

Well I'll tell you, I mean that

1	the U.S. Preventive so the U.S. Preventive
2	Service Taskforce viewed as the relevant
3	outcome was employability, school function.
4	That was the outcome.
5	The debate was sort of the quality
6	of the literature that linked early screening
7	to those outcomes and what ultimately
8	convinced them was I think enough studies
9	feeling that the bias involved in those
10	studies didn't wasn't sufficiently strong.
11	So that's what got it to be a
12	recommendation over time, but it really was
13	based on the long term outcomes.
14	We made the argument, and we in
15	this group can make the argument that for
16	example parental satisfaction, which clearly
17	parents are much more comfortable knowing that
18	their child has whether their child can
19	hear or not, but we made that argument.
20	And I still think it's valid. We
21	did not convince the taskforce, at least at
22	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 3 4 your initial process is screening, the outcome 5 -- the intermediate outcome would be treatment because if you didn't, you know, and then the 6 7 treatment is an intermediate step towards the more longer term outcomes that you were 8 9 talking about. 10 So perhaps you could make the 11 argument for --12 CO-CHAIR HOMER: Treatment by six 13 months for example which is what the --14 DR. WINKLER: Whatever it is, yes. 15 DR. DOCHERTY: Or another way to look at it, if you know, depending on where 16 the service is expected to be, so when 17 something is, you know, well known, a process 18 is well known to lead to an outcome like 19 20 screening we now know and it's been supported in the literature for decades that if you 21 22 screen you get these outcomes, then doesn't

that process then become an outcome in a
 particular service.

3 So, you know, in these -- where 4 the screening is supposed to be done, then it 5 becomes an outcome for them not a process 6 because it's supposed to be done there. We 7 know it leads to this.

8 CO-CHAIR HOMER: I think it still 9 gets down to the strength -- it's a balance of 10 I think the strength of the linkage and then 11 probably the feasibility and the time delay of 12 the -- that would be my guess.

13 So for example, I keep hearing it 14 doesn't seem reasonable that you have to measure whether somebody can have a job and 15 graduate from high school, which was what the 16 studies -- that's what the taskforce was 17 holding, that doesn't seem reasonable to me. 18 But whether having, for example, a 19 20 newborn hearing screen done, which is clearly a process is in itself a sufficiently -- would 21 22 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.

4 DR. DOCHERTY: I was just going to 5 say I would argue that for certain services it's an outcome then because we know that it 6 7 has to be done in order for -- the process then becomes an outcome over a period of time. 8 9 It's like thyroid screening now, 10 you know, for infants, it's now an outcome. You don't have to wait for the disease -- to 11 ensure that quality care is being given. 12 13 CO-CHAIR HOMER: It wouldn't fit on our list so for example thyroid screens, 14 that's an even clearer one that wouldn't fit 15 on our lists that we could either modify the 16 list to include it. 17 18 DR. WINKLER: I think what you're getting at is something much like Tom was 19 20 talking about was proxies for outcomes like immunization rates because, you know, not 21 22 getting something is really the outcome, but

1 that becomes pretty hard to measure.

2 So actually the receipt of the 3 immunization, which is the protective element 4 may be the more feasible outcome or proxy for 5 the outcomes that you can measure and the 6 question is, are there others of that ilk 7 which I think puts us in the gray zone in 8 terms between process and outcome.

9 And we may not have any of these 10 measures, you know, it will just depend as we 11 try and characterize the call for measures 12 what we're looking for. We do need to kind 13 of, you know, figure out where the boundaries 14 are and that's what this conversation is sort 15 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

1 of confidence in and come back.

2 CO-CHAIR WEISS: I agree. DR. WINKLER: This is looking to 3 sort of form the basis of the call, but I 4 5 think there's more to it than that and we do want to talk about some other elements of it. 6 7 A couple of things, if you go down to the next slide Melissa, this was something 8 9 that was brought up by members of the main 10 steering committee that I thought were very interesting for you to consider and that is, 11 you know, the source of information about 12 13 outcomes. And they really kind of boiled 14 down to three, the patient reported outcomes 15 folks, the world they live in, use this 16 construct. And one is information that you 17 get from the patient or caregiver. You know, 18 they're doing the observation. This is sort 19 20 of your history if you're the clinician it's 21 like, you know, what happened, did you get 22 better, can you do something.

1 CO-CHAIR HOMER: Or pain for 2 example. DR. WINKLER: Or pain, did your 3 4 pain go away or can you do, you know, can you 5 resume doing whatever it was you couldn't do 6 and that's the reason you came to see me. 7 But the information comes from the patient. And then other information about 8 9 outcomes could be clinician observation, an 10 assessment, you know, decreased leg edema after instituting treatment, you know, 11 diuretic therapy for your heart failure, 12 13 whatever, any of those sorts of things. And then the other outcome is more 14 -- other type of outcome information would be 15 physiologic which is something you could 16 measure that is measurable by anybody, blood 17 pressure, the lab result, whatever. 18 In fact, one of the interesting 19 20 things that the IT folks are dealing with is where does data come from and it's conceivable 21 22 that things like blood pressure measurement

1 don't come through a clinical per se, but come 2 from the machine that someone took the 3 measurement with.

4 So these are the more, you know, 5 same thing with a lab result, so they're much more objective, physiologic kind of 6 7 perimeters. And so the question would be is it desirable to have outcome measures that 8 9 utilize all of those sources of information. 10 Because there are some people who 11 feel like the patient reported outcome side of 12 it, either too hard to do, too squishy, I 13 don't know, something. But do you feel that all of those would be important to be sure we 14 didn't, you know, deliberately exclude any of 15 16 those as potential outcome information. 17 DR. RAO: Reva just a question, on patient reported outcome, does that include 18 documentation by a clinician of improvement or 19 20 is it directly collected from patients?

21 DR. WINKLER: I mean I think that 22 would depend on how a measure could be

1	specified. I mean I could see it both ways.
2	I could see you documenting a
3	series of standardized questions on like a
4	patient with asthma, you know, have you missed
5	school in the last three any days of
6	school, have you done this, have you done
7	you have a standard set and that would be
8	documented in your chart, in your EHR easily
9	retrievable data elements.
10	But it also could be a survey. So
11	I don't think we're being prescriptive about
12	it, but I think there are potential options
13	for getting this information.
14	MS. PARTRIDGE: Reva, would your
15	physiological include things like hospital
16	admissions? Is that
17	DR. WINKLER: I would imagine it's
18	pretty I mean it's pretty yes, it's a
19	fact.
20	MS. PARTRIDGE: Yes.
21	DR. WINKLER: Nobody has to
22	observe or interpret it just is. Yes, I would

guess so. The group that does this uses 1 physiologic and I always call -- I kind of 2 think of it as objective. I mean just very 3 4 fact based. I mean there's no interpretation 5 necessary, it just is. DR. PERSAUD: 6 I quess I'd be 7 reluctant to exclude anything because I think the way you get the information might not be 8 9 telling you whether something's necessarily an 10 outcome. As Charles point out, patient 11 satisfaction surveys, and in the STEEEF the patient-centered perimeters are going to be 12 13 patient reported, there is mostly. So I'd be reluctant to exclude anything. 14 15 DR. ZIMA: Yes. I struggle a little bit with physiologic because we've 16 already talked about service use. And we 17 might want to go back again to Donabedian 18 roots and what probably call that type of 19 outcome and absolutist outcome and which is 20

21 kind of like the no-brainers, the concrete

22 ones.

1	So vital signs, lab results, we've
2	had some discussion about service use and, you
3	know, is that the place we also put treatment
4	adherence. So for example, you know, plasma
5	levels of a certain drug, right, or Medicaid
6	claims data. Agency data is not one of the
7	data sources up there, should they consider
8	that?
9	DR. WINKLER: Yes. I think I
10	probably shouldn't have used the word data
11	source as, you know, data stream, if you will.
12	The question who's creating the information
13	not necessarily how it came to you.
14	MS. PERKINS: This is Jane
15	Perkins, I'm going to have to get off and go
16	to this other thing, but I'll join you again
17	in the morning.
18	CO-CHAIR HOMER: Thank you Jane.
19	DR. WINKLER: Thank you Jane.
20	MS. PERKINS: Thank you very much,
21	bye-bye.
22	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.

7 Then when you ask the specific 8 questions, you find out there is a problem. 9 So I would suggest that patient reported 10 outcome needs to be by structured set of 11 questions.

12 CO-CHAIR HOMER: And again, are we 13 differentiating or would we elaborate on this 14 to include families.

So again, I just think it's useful 15 to do that and do we want to broaden, and 16 maybe again broaden this to include other 17 sources like teachers -- again if we're going 18 to include school performance, for example, 19 20 and then the other question is if we're going 21 to include broader measures of public health. 22 Now I assume that most of those

data are still going to be coming either from 1 the child or from a professional's observation 2 of them, but it isn't necessarily the 3 I'm sorry, David and then Tom. 4 clinician. 5 DR. CLARKE: Well one thing that's not up there, and I'm not sure if it fits into 6 7 one of the other categories is the various registry databases that exist. You know, this 8 9 is clearly from my experience with data 10 audits, it's not exactly absolutist, but it's 11 not bad. And so I'm not sure whether that 12 13 is kind of a separate source or if that would be under clinician observed outcome. 14 15 CO-CHAIR HOMER: What's the input into the registries that you're talking about? 16 DR. CLARKE: Well it's a whole 17 bunch of data cells regarding the patients 18 hospitalization or surgery or all kinds of 19 20 data and it's usually rather than clinician 21 it's entered by a data manager. 22 DR. WINKLER: Well I think though

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1 that the data manager would get any clinical 2 data from the patient record which is 3 clinician generated, with the exception of 4 things like the lab results and the vital 5 signs and the, you know, the more objective 6 data.

So in those cases, because it's a 7 large data set would probably be a mixture. 8 9 So it's not meant to, you know, this was meant 10 to be just an idea of keeping in the patient reported outcomes as well as the more 11 traditional objective information as well as 12 13 the clinician generated information and be sure that we all want to include that. 14 Because I think being explicit 15 when we do our call for measures would be 16 17 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

1 oh just fine.

2	But, you'd really want to see
3	what, you know, what are his marks, is he
4	getting 80s, 90s, 60s, 50s, what and you'd
5	have to be a little bit careful.
б	DR. WINKLER: Okay. Bonnie, I
7	think it's your turn. Yes, I just I think
8	we've introduced Bonnie Zell and Bonnie is our
9	population health expert at NQF. And so she
10	wanted to talk a little bit about population
11	and see how you all think that we might be
12	able to bring all this together.
13	DR. BURSTIN: And just one more
14	framing piece before Bonnie starts. I think
15	that, you know, the child health piece in
16	particular can get fairly expansive as you
17	begin to think about outcomes, the point you
18	just raised for example, about, you know,
19	grades in school.
20	So I think we wanted to have
21	
	Bonnie give what's intended to be an expansive
22	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.

4 DR. ZELL: I appreciate that. Ι 5 appreciate the opportunity to talk with all of I mean, when you're talking about 6 vou. 7 children and you're talking about health, this is child health outcomes. 8 9 I think it's really important for us to kind of understand what we're talking 10 about when we're looking at different 11

12 denominators. And so I will address that as13 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.

21 And because we're talking about22 children who's level of ability to perform is

1	influenced from the day they're born and
2	really impacts them the rest of their lives,
3	it's really an important issue for us here.
4	What we're often talking about
5	when we're talking about outcomes is disease.
6	It makes a lot more sense when we do that for
7	adults, because adults are a lot sicker.
8	When we're talking about children,
9	it's a very small number of children that
10	intersect with the health care delivery system
11	with some kind of problem. So I think that's
12	really important for us to remember and how do
13	we think this through.
14	We do talk about children's health
15	when we're talking about screening and
16	developmental milestones, but then we very
17	quickly jump to we're only now going to focus
18	on disease focused outcomes pretty much.
19	So when we're talking about
20	population health, the World Health
21	Organization states that it's more than just
22	an absence of disease, it's gone some a

1 positive aspect to it.

2	And the Institute of Medicine
3	talks about that, but I just really want to
4	point out at the bottom here that they state
5	explicitly that it's a shared responsibility
б	of health care, governmental public health and
7	a variety of actors in the community.
8	And so it's very complicated to
9	figure out where the boundaries are when we're
10	talking about children. Next please.
11	So I thought it would be useful to
12	just kind of walk us through, how does health
13	really happen and what does it mean when we're
14	talking about individuals and then when we go
15	to population health, because really they're
16	one in the same.
17	Health happens one person at a
18	time, one day at a time, one decision at a
19	time, but within the context of where and how
20	people live. Not all of us have the same
21	choices.
22	So it's impacted by where we work,

where we go to school, where we play, where we 1 shop. It's influenced by the socioeconomic 2 things that we always talk about, education, 3 income, employment determined by the access to 4 5 health foods, safe environments, available transportation and health care services. 6 7 But it doesn't happen primarily within health care, especially when you're 8 9 talking about children. And it does happen 10 within the context, as we were talking about here a lot today in terms of preference 11 choices, cultural, social and economic 12 frameworks and these individuals then 13 14 aggregate to populations. Next. And that is the only thing that a 15 population is, is wherever we decide to draw 16 the boundary around individuals, whether it's 17 racial, ethnic, disease specific, life stage, 18 level of poverty. 19 It can be all the different ways 20 we'd cut it within health care whether it's a 21 22 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.

4 It can be geographic region, which
5 also has a very big impact on health or it can
6 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

1 work together. Next.

2	This is healthy people in healthy
3	communities. This is IOMs look at the future
4	of the public's health in the 21st century and
5	it demonstrates right from the center of this
6	diagram, the importance of the conditions that
7	need to be addressed for health, next, and the
8	roles that all the different sectors play.
9	This is the chronic care model,
10	which I'm assuming everybody here is familiar
11	with. But this is the expanded chronic care
12	model that really places the health system
13	within the community in which it sits. And
14	it's really important for us to remember that.
15	There are things that we do in the
16	health care system that do not get done
17	outside of the health care system that are
18	critically important.
19	There are things that are done
20	outside of the health care system that the
21	health system itself does not the health
22	care delivery system does not specifically

address, but many things that we could and 1 2 many areas where we overlap and opportunities that exist that we can influence those things 3 that we often don't that we also need to 4 5 consider I think. 6 And I think that it's also just 7 really important to understand that we do want activated, informed patients and families, but 8 9 also communities and community partners. 10 Next. This is a driver diagram that was 11 12 put together by a group in Wisconsin. I don't 13 know how many of you are familiar with something called the Wisconsin County Health 14 Rankings. 15 And these have been produced by 16 the University of Wisconsin Population Health 17 Institutes since 2003. They developed this 18 driver diagram that if you look, there's 19 health outcomes which looks at mortality and 20 then self-assessed health status. 21 22 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.

11 And you can obviously keep breaking all of these down, but it really 12 13 emphasizes the significant impact that these other health determinant regions, health 14 behaviors, socioeconomic and physical 15 environment have and it goes down to the 16 specifics to many of the things that we've 17 been talking about here, high school 18 graduation rates, et cetera. 19 20 DR. JENKINS: Was that intended for adults or for kids? I'm just curious if 21 the breakdown is the same for kids as for 22

1 adults.

2	DR. ZELL: I would say this was
3	really done for populations in general. It's
4	a community health index, so it definitely has
5	indicators in there for children such as
6	things like graduation rates are in there,
7	things about health education for teenagers,
8	et cetera.
9	So it definitely has indicators in
10	there. I wouldn't say that it's got
11	everything by any means, but this is something
12	that we're going to be working with as a
13	beginning in the National Priorities
14	Partnerships for the population health
15	community health index, which is something
16	else that we can talk about.
17	But I think what's really valuable
18	about this process that they've done is that
19	it's been recognized as something that is
20	really gotten county level attention within
21	Wisconsin, has motived a tremendous amount of
22	intervention, discussion and action.

1	Because of that, Robert Wood
2	Johnson Foundation funded them recently to do
3	these county level rankings for every county
4	in the United States. That will be released
5	in February of 2010.
6	What's important to know about
7	these are they it's a very powerful process
8	in that it has garnered a lot of attention and
9	discussion, but when you're talking about
10	action, everything is local.
11	And we really need to take this
12	county level information and understand that
13	we need to look at this from a population
14	standpoint, we need to bring it down to
15	neighborhood and community levels so that we
16	know what to do where, because doing it in a
17	blanket fashion everywhere is not the best use
18	of our resources we need to target. Next.
19	So defining population
20	relationship to health care, I thought it
21	would be useful just to talk a little bit
22	about how to bring population level

1 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.

9 But I -- my background is a nurse 10 and then an OB/GYN physician for 20 years and practice at Kaiser in California and never 11 once did we ask that question when I was 12 13 there. I did not have any idea how many patients I had with a specific disease or a 14 specific age breakdown, how many women at mid-15 life did I have that might need X et cetera. 16

17 So it's a very powerful way to 18 just look at our own data. It's not hard to 19 do, it's data that we're already sitting on, 20 but it really gives us a very different view 21 of what to do rather than waiting for just 22 individuals to come and knock on our doors.

1	
1	What is it that we need to do
2	proactively for the populations that we serve?
3	Another is to utilize publically available
4	data to better understand community context
5	and populations by using some of the tools
6	that we have now such as GIS mapping.
7	So taking those same individuals,
8	plotting them out on the map, overlaying that
9	with some of the publically available data
10	whether it's looking at asthma patients and
11	air quality et cetera. You can do this
12	there's over 600 layers of free publically
13	available data.
14	And I'm working on some projects
15	to do just that have just demonstrated
16	incredible power. We're looking at congestive
17	heart failure patients in one health system in
18	Atlanta and just by asking questions that we
19	had not asked before, we learned just amazing
20	things such as some people had been admitted
21	20 times in three years.
22	But because it was just patient

was readmitted and we hadn't asked those types 1 of questions. So, what was amazing to me is 2 I posed a list of 20 questions that were 3 really -- provided a lot of insight in how 4 5 easy it was to query their data to get it. It was just by ICD-9 codes and all 6 7 these things would popup. So it's a different way to -- it's a different lens to 8 look at what we do. Next slide please. 9 10 And then, you know, again when people talk about well that's health care, 11 that's individual interventions versus that's 12 13 public health, it's really a matter of understanding that there are both individual 14 level strategies and interventions and there 15 are population level strategies and 16 interventions and how to bring some of those 17 into health care. 18 So for instance, if you've done a 19 20 query and you understand your population, 21 whatever that -- whatever way you've cut it, you could do targeted outreach for screening 22

and follow up instead of these blast things 1 that we do, we could really target what we do 2 to specific segments of the population so that 3 we can, again, utilize our resources in a much 4 5 more efficient fashion. 6 Suggest available community level 7 health care and health promotion resources targeted to specific populations. 8 9 Again, when we're talking about 10 health care versus where these fuzzy borders are, there are a lot of opportunities for 11 health care to disburse itself into a 12 13 community to provide health related services that are still considered health care in a 14 sense, but really impact health on a different 15 level; disseminate newsletters, provide 16 healthy recipes, partner with community 17 stakeholders, schools, businesses and faith-18 based et cetera. Next slide please. 19 20 So, in addition to assessing did 21 Alissa get her peak flow, her home management 22 plan and a corticosteroids prescription, can

we also ask how many individuals that we care 1 for in our practice have asthma and what 2 percent of our asthmatic patients have had the 3 4 peak flow over the last 12 months of home 5 management plan, et cetera composite measure. Next slide. 6 7 I think it was really interesting some of the conversation that's happened 8 9 earlier today where a lot of these types of 10 issues came up and I just thought I would put

12 something to think about in terms of

some things up there that might give us

13 conversation in thinking about where the

14 boundaries are again.

11

15 So here's looking at prevalence of 16 obesity among U.S. children and adolescents 17 aged I think it says 2 to 19. And it's broken 18 down by different ages on the bottom and it 19 shows you what's happened.

20 This is NHANES, which is a federal 21 program of evaluation across the United 22 States, and it shows what's happened from I

think 19, I can't see it myself, but it's 1 like, okay so 1971 and the last is the 2003 to 2 2006 NHANES shows you what's happening by age 3 and over time. 4 5 And clearly we have been, you know, we in health care, we measure BMI, we 6 7 might suggest to parents and educate them about what kids should eat, educate them about 8 9 exercise. 10 We might be able to check those 11 off and get really good scores in health care, 12 the question that we have to ask is how far 13 out do we go and how do we work with other sectors to make sure that the conditions exist 14 so that the things that we're suggesting are 15 actually doable. 16 Meaning, is there access to the --17 let's talk about kids, in schools to healthy 18 foods, recognizing that we're talking about 19 20 health care, but if that's a concern of health care and if child health is a concern of 21 22 health care, where do we draw these

1 boundaries.

2	What can we do, doesn't mean we
3	have to necessarily be accountable for what
4	goes on in schools, but can we have joint
5	accountability with schools or can we work
б	with schools to make sure that they have the
7	meals that they need to have and the physical
8	exercise, et cetera. Next slide.
9	This just shows what's happened
10	over time from the NHANES 1988 to `94 and the
11	next one which was 2003 to 2006 to again show
12	the need to look at things from a segmented
13	fashion.
14	This is looking at the difference
15	between boys and girls and the difference in
16	race and ethnicity and you can see that
17	there's a huge difference in both. Next
18	slide.
19	So as I already posed, should
20	other sectors in the community that
21	significantly influence health status in
22	addition to health care have accountability

for health in their communities, and if so, 1 how might we connect performance measures in 2 health care with activities in other sectors? 3 4 A question just for us to talk about. 5 School nurses, I met a school

nurse at a meeting just over the weekend who 6 7 was talking about their interest in working more closely with health care, their nurses 8 9 and the issue of community benefit and how 10 community dollars are spent from hospitals, non-profits being required to spend a certain 11 amount of money in community benefit. 12

13 Is there an opportunity there to think about how health care could get involved 14 in these types of issues? Next slide. 15

16 Can we expand our frame, and you're working on your framework from why does 17 this patient have this disease at this time to 18 what population circumstances are the 19 underlying causes of the disease incidents in 20 this population. Next slide. 21 22

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.

8 Because when we're talking about 9 children in general and doing the screening 10 and the milestones, we're talking about the 11 entire population. When we're talking about 12 those afflicted, we're talking about that just 13 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.

21 And the importance, I think, of 22 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 8 9 that I put in here. The Association for 10 Community Health Improvement is part of the American Hospital Association that did an 11 excellent steering committee report on 12 13 hospital's role in communities and their role in the public's health with many suggestions 14 of what could be used, what could be done from 15 a health care standpoint and a lot of 16 information there about what I mentioned 17 before using community benefit dollars. 18 The U.S. Preventive Services 19 20 Taskforce is a resource that talks about community level, population level 21 interventions that have been demonstrated 22

1 through science to have impact.

2	So for instance, there was one
3	study in that in 14 out of 14 studies that
4	demonstrated that those schools that had
5	moderate to vigorous physical activity
6	mandated for kids, 30 minutes, at least 30
7	minutes a day had absolute decrease in BMI,
8	they all had improved aerobic fitness and it
9	went to the issue that somebody brought up
10	earlier in terms of maximal function.
11	So there's a lot of different
12	tools here, I thought I would just share that
13	had a lot of different interventions, guides,
14	ideas, et cetera. But I do think it's
15	important when we're thinking about outcomes
16	to think about health outcomes as well as some
17	of the outcomes we've been focused on. Thanks
18	very much.
19	CO-CHAIR HOMER: Thank you Bonnie.
20	Tom?
21	DR. MCINERNY: Well of course, the
22	Massachusetts has instituted a couple of

1 changes and I'm not sure whether they're 2 improvements or not, but certainly universal 3 health care for everyone and how has that 4 affected the health outcome of children. I 5 don't know if anybody's looked at that and 6 where they are with that.

7 And then the other is the mental 8 health project to divide the state up into six 9 regions and provide consultative services for 10 the primary care physicians and I know that's 11 two or three years old now and I'm not sure 12 what the health outcomes of that has been 13 either.

CO-CHAIR HOMER: 14 Two qood questions. We could find out more I think 15 16 short answer on the health insurance, again, we had relatively low health uninsurance for 17 kids before the expansion, we now have even 18 I think it went from -- but it already 19 lower. 20 was quite low.

21 And I think in terms of health22 status, I don't know. I don't think we've

1 seen the health status effect yet. Mental health is a good one, there was both that and 2 then there's more recently what's called the 3 Rosie D. Settlement which is an even more 4 5 expansive mental health program. But to be determined. We'll send 6 7 Reva home to do some homework and see if -- no I don't think there are yet any measures of 8 9 impact of those societal changes. But those are largely, to Bonnie's 10 11 point, those are largely health care service changes rather than some of the broader 12 13 changes that her report was at least suggesting we bring on to the table for 14 consideration, you know, which would be more, 15 again to use the parochial Massachusetts 16 17 approach. 18 Massachusetts also launched what they call Mass in Motion which is more about 19 20 in addition to providing health services it's, you know, getting the wise involved and 21 building more sidewalks and changing school 22

lunches and, you know, all the broader array 1 of interventions that are going to address the 2 particular issue of obesity. Donna? 3 4 DR. PERSAUD: Thank you. That was 5 an outstanding set of slides that I would like to borrow is my first request if that's 6 7 possible. I really like the integrated way that you have the concepts listed up there and 8 9 all the resources. 10 And I think that I guess being the 11 prevention minded pediatrician it's an interesting thought to come up with joint 12 13 accountability for measures. And if it's not even in scope for 14 what we're supposed to do, I think we have to 15 acknowledge that some of our limitations might 16 be because we're not getting to joint 17 accountability. 18 And some of what I talked to in 19 20 our community care we realize that the obesity 21 epidemic is such that the answer is not going 22 to be find every child a doctor and get them

a check up every year. It's going to be joint 1 2 accountability with other entities. So it would be neat and maybe 3 that's the future of this to begin to use 4 5 those concepts in the conceptual framework. And I am actually coming, I don't know where 6 7 we'll be doing the conceptual framework brainstorming, but I've got maybe a 3D idea in 8 9 my head coming up that it's not going to be 10 flat, it might be 2D I think there's a chance it could even be 3D. 11 12 DR. ZELL: Could I comment on 13 that?? CO-CHAIR HOMER: 14 Please. Because I think that 15 DR. ZELL: 16 what you're bringing up Donna is really important that I think, and I'm not sure what 17 the answer is, but I think we tend to try to 18 boil things down to something very simple and 19 linear and in fact what you're saying with 20 three-dimensional I would call complexity. 21 22 It's very complex and especially

when you're talking about child health. 1 Т 2 think we have to understand the complexity of it and all these different factors that 3 4 interrelate and somehow acknowledge that. 5 And I think be explicit about where we're -- I mean if this group decides 6 7 that it's just really health care focused on the traditional sense, I think it should be 8 9 stated so explicitly. 10 DR. JENKINS: I want to echo what Donna said and thank you very much for that 11 presentation and it was a little bit what I 12 13 was alluding to before about this population based health. 14 But I guess I have a guestion then 15 for Reva or Helen, again related to scope. 16 Ι was making the assumption that these were 17 going to be NQF endorsed measures of health 18 care but I heard you say at like the very 19 20 beginning that NQF also has a priority setting for health over all mission. 21 22 And is there anyway that this

1	process could perhaps influence that priority
2	setting process rather than just the
3	measurement endorsement or is that out of
4	scope for us?
5	DR. BURSTIN: No that's very much
б	within scope. The National Priorities
7	Partnership has already identified population
8	health as one of the six national priorities
9	and within that delineate a real focus on
10	preventive services screening, healthy
11	behaviors and this general concept of sort of
12	a community index of performance.
13	I think there is a very open
14	question as to whether over time there is an
15	expectation. Perhaps we'll get some measures
16	for which accountability can't be solely laid
17	at the heals of the health care system. And
18	it may be now.
19	We've already, for example,
20	endorsed the set of AHRQ prevention quality
21	indicators which indicate preventable,
22	potentially preventable admissions of a

1 community. They're community level indicators 2 and it's very hard to specifically assign accountability for whom that, you know, that 3 admission could be potentially related. 4 5 But at the same time, there's a recognition that's an important quality 6 7 measure for us at the community level. So I think that's what we wanted to bring to you, 8 9 get your sense of it. 10 I mean, you know, as Bonnie and I were talking about this, she clearly goes 11 further than my comfort zone, but this is 12 13 where she lives. But, you know, I think there may be measures where we were beginning to see 14 some coalescence of some of these different 15 16 sectors coming together. And I think especially in this 17 group, it's hard to imagine you wouldn't want 18 to consider schools as a logical locus within 19 20 which, at least for me it's the interstices, 21 you know, can you at least think about 22 measures that maybe get us closer towards

1 understanding those linkages, those 2 connections those opportunities for collaboration that could improve kid's health. 3 4 DR. PERSAUD: Actually just very 5 quickly, the last mock Joint Commission survey we had, the surveyor came in and asked us 6 7 whether we assessed cognitive and academic performance of children with asthma to help 8 9 them in their self-management. 10 And that would be a great example of how that circular where your health care is 11 going to effect their ability to handle school 12 13 and their ability to achieve in school is going to effect their ability to manage their 14 medications and their asthma action plan, so. 15 16 DR. JENKINS: I also think laying out a complex framework is actually protective 17 about inappropriate use of measures in certain 18 19 -- at context. 20 Just to make the point in Massachusetts, we've had bitter battles with 21 22 our major payer over whether or not

1 pediatricians could be held accountable for 2 reductions in rates of obesity or whether that's beyond scope of what they can 3 legitimately be accountable for. 4 5 And so if the whole framework was laid out, it will also be protective against 6 7 inappropriate use of measures. So far they've rejected the opportunity to be accountable, 8 9 but just barely been able to make it through. 10 CO-CHAIR HOMER: The thing is the payers wanted to hold the accountables -- the 11 providers accountable --12 13 DR. JENKINS: For reductions in 14 rates of BMIs and actual improvements towards normal and the pediatricians have marketably 15 rebelled against having money on the table for 16 that because they do not believe they can 17 18 influence it. DR. ZIMA: This is the first time 19 20 I've met another Dr. Bonnie Z. MD, MPH and it's amazing because, you know, we struggle so 21 22 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, 4 5 particularly in California, the state funded legislation for mental health, those outcomes 6 7 are in there. And I think one of the examples right now we have is the California Mental 8 9 Health Service Act where mental health dollars 10 are being justified to reduce things like homelessness. 11

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.

18 CO-CHAIR HOMER: I personally
19 think that's certainly in our scope to at
20 least -- I think we definitely need to look
21 broader than just academic performance, but
22 look at those issues like recidivism and like,

you know, jail rates or whatever the --1 incarceration rates, that's the word I was 2 looking for and those to violence, youth 3 violence, a variety of things that are outside 4 5 the typical scope. 6 DR. ZELL: Has everybody else had 7 a chance? DR. WINKLER: I think one of the 8 9 things that when we do this call for measures 10 when we look at potential measures out there, 11 considering the population focus, if you look 12 at the measures we've already endorsed, there 13 are quite a few of them who's denominators are per 100,000, all right. So certainly NQFs 14 been down that road before. 15

And the question would be, you know, to what entities can that be applied? Noes 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.

1 So that it's sounding, from your 2 comments, that the kinds of measures, the kinds of what we call population measures 3 4 where you have the denominator is something 5 like per 100,000 or per 1,000 or something like that, would be measures you would want to 6 7 consider. Would you want to keep in the box 8

9 as opposed to exclude them, though they will 10 have their limits and their applicability can 11 only be, you know, might be different than 12 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 publicmental health it's a little bit easier to go

down that slope because it's all public 1 2 dollars and then we talk about cost shifting and that we've kind of justified mental health 3 services because we ideally reduced cost and 4 5 probation or something like that. But I don't know -- I mean it 6 7 raises sort of another level of complexity about when the responsibility in a privately 8 9 insured company is not owning responsibility for the societal outcomes. 10 DR. WINKLER: But wouldn't they be 11 12 responsible for their population of enrolled 13 or folks that are part of their system as a population. 14 And that I think was a lot of what 15 Bonnie was talking about was, you know, not 16 just who walks through the door, but if 17 they're part of your group, define the group 18 however you want, but if their yours, do you 19 20 have accountability for the entirety of the 21 group and not just the active ones? 22 I think that's a good DR. ZIMA:

1 question.

2	DR. PERSAUD: I think what you
3	said with, you know, as long as we define the
4	limits of applicability of the measures and I,
5	just speaking as an end user and knowing
6	what's going on in the communities, I do think
7	more and more coalitions and communities want
8	to galvanize resources around what should be
9	the benchmarks.
10	And I think I'm hearing, and I am
11	one of the needers of those kinds of measures,
12	but I do think we should be very prudent about
13	defining the applicability and the
14	reasonability to, you know, who's using it and
15	why.
16	CO-CHAIR HOMER: Do we want to try
17	come up with a threshold, I mean it's there
18	are no data on this, but do we want to come up
19	with some threshold of proportion of, you
20	know, attributable risks or accountabilites.
21	So for example, your BMI in Massachusetts, you
22	know, could we reasonably attribute to the

1 health care sector, you know, X proportion of 2 accountability?

I mean, on the smoking -- so for 3 example, on the smoking issues on the adult 4 5 side, so for example, obviously people are -plans are held accountable for counseling 6 7 about smoking cessation, are they held accountable for the proportion of the 8 9 population that smokes is I guess the next 10 questions. I mean, that's a held behavior. 11 Т

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 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.

1	CO-CHAIR WEISS: I honestly I'm
2	seeking information here, I honestly don't
3	know the answer to this. Are there studies
4	that we could look to that would give a sense
5	of what compliance rates for various of these
6	measures would be? Average by cutting it by
7	type of population or region or whatever?
8	DR. WINKLER: Marina, one of the
9	things we ask for in the measure submission is
10	that sort of data. And even those that
11	provide us with a large amount of data
12	actually it's relatively limited to your
13	question was extremely expansive.
14	I mean I'd love to have, you know,
15	wide ranging data on all sorts of things and
16	stratify them in a 1,000 different ways, but
17	that's very rarely available. So to the
18	degree data is available, usually whoever the
19	measure developer is, they're using it for
20	whatever their purpose in developing the
21	measure was and they will have applied it to
22	that group.

1 Sometimes it's big, and sometimes it's very narrow and it tends to be somewhat 2 variable. Whether there's additional 3 4 information, except in some of the large 5 measure developer activities where they publish as a result of some of it, it's really 6 7 hard to find. And if you all can help us with that, that would be grand. 8 9 DR. RAO: But Reva isn't one of the criteria for submission -- a basic 10 criteria for submission of a measure is that 11 they have to identify a significant problem? 12 13 You can't put in a measure, for example, where everyone's, you know, giving out influenza 14 immunizations already sort of --15 DR. WINKLER: Well they can submit 16 it, but it should fail on, you know, some of 17 the criteria in terms of usability, in terms 18 of importance around is there a gap and 19 20 variation in care, is there a quality problem associated with it. So they can submit, but 21 22 it would have struggles against some of the

1 criteria.

2	CO-CHAIR WEISS: Well let me just
3	suggest then that maybe we would like to think
4	about this by changing the paradigm a little
5	bit and maybe instead of looking for someone
6	to hold accountable in these areas where it's
7	an entity, an organizational entity to hold
8	accountable where it's iffy, maybe we put this
9	issue of measuring true outcome in the basket
10	of items on which we would like to see
11	additional work done, I mean.
12	DR. LIEBERTHAL: Charlie mentioned
13	the idea of apportioning to the health care
14	system part of the outcome and I think that's
15	a very slippery slope because I don't think
16	there's any way to collect data that would be
17	applicable.
18	However, in using outcome data for
19	things that are primarily health care related,
20	take asthma, again, using the asthma example,
21	by comparing organizations or health care
22	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 4 asthma rates and we do have, Bonnie, I don't 5 know when you left -- were you in Northern or 6 7 Souther Cal? Northern. I think you have some of the same systems as we have, but we have 8 9 some very robust systems for measurement, 10 population measurement that can be broken down by medical center office, provider, et cetera, 11 12 et cetera.

13 How we use them is another story for using them robustly or not. However, if 14 you have a measure that is a valid measure and 15 16 you put the Kaiser Health System up against United Health Care and against Blue Cross, et 17 cetera, et cetera, now you have a comparison 18 against which health care organizations can be 19 20 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.

5 You could even stretch this to 6 school systems again using the adjustment, 7 what is the obesity rate in a school system and what should a school system be doing to 8 9 deal with the education or break up any 10 comparable populations and compare then against each other. So this is one way that 11 12 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.

6 So they are far reaching and 7 that's the intent. And I think what we're 8 trying to get at is, there may be a set of 9 measures that are the best measures we need to 10 move the nation's health.

I think what you're kind of 11 getting at Kathy is there are issues where the 12 13 accountability locus isn't always clear and assigning accountability can be complicated, 14 but it may still be that a measure that looks 15 at the reduction of obesity in a community or 16 in a accountable care organization or in a 17 public health system is very appropriate. 18 19 But I think the key thing is 20 thinking about what the appropriate level locus of accountability is, but still the 21

22 right measure we should endorse should still

be the one that gets us to the right place. 1 So question, because I 2 DR. ZIMA: think when we talk about joint accountability 3 there's also that whole problem with data 4 5 sharing and data linking across the sectors. So in thinking, you know, when you 6 7 say, okay that's a future research agenda item, when we start thinking about the 8 9 measures, should we also be identifying other 10 data sources that would require linking in order to measure that outcome? 11 12 CO-CHAIR HOMER: We have the 13 privilege of not actually having to develop the measure. We don't do any measurement 14 development here, so we -- but we do need to -15 - I think the question is, who would we be 16 soliciting and eliciting measures from? 17 DR. ZIMA: It's an exercise 18 because it nicely kind of stimulates I think, 19 you know, Marina says, okay let's put that on 20 21 sort of the future agenda, you know, that 22 these are things that we think are important

like recidivism or reduced foster care
 placement.

But is that within the scope of 3 this committee to sort of at least identify 4 5 that oh, that would require data linking that right now existing health care data bases 6 7 aren't allowed to do for HIPAA or whatever? CO-CHAIR HOMER: I mean again, 8 9 typically what would happen would be we could 10 identify a whole bunch of things and then either ourselves opine about what would be 11 needed for it or that often would lead NQF to 12 13 create some workgroup that's going to elaborate on that. I think that's what 14 15 happened on the care coordination process. 16 CO-CHAIR WEISS: Another way we might go, for example, is to do a spreadsheet 17 and on the far right column say, this 18 particular measure lends itself to a 19 20 population wide reporting system. So we could flag it and say this has -- this particular 21 22 measure has added value in the population wide

1 arena.

2	CO-CHAIR HOMER: Why don't we take
3	the two questions that are on the floor and
4	then I think we're due for a break. So Tom
5	and then Lee.
6	DR. MCINERNY: On the population
7	thing, I think one of the most important
8	lessons that we need to get across to
9	physicians and providers is to measure the
10	health of their entire population of patients.
11	All too often, you know, we ask
12	the physicians, you know, how's your
13	immunization rate, oh it's great, 90 percent
14	of my patients are immunized. But then when
15	you ask them to actually go and look at all
16	the patients that are in their practice, oh
17	gee, you know, these kids, I don't see these
18	kids very often and they don't have a very
19	good immunization rate.
20	And then all of the sudden, whoa.
21	And unfortunately, it's the rare practice, in
22	my experience unless maybe in Kaiser or some

other program like that, that has a clue of 1 2 how many patients they have and how well immunized or how many patients with asthma 3 they have even and how well they take care of 4 them. 5 You know, if you ask a 6 7 pediatrician name all your patients with asthma, they can come up with three or four 8 9 and then they start to wonder, gee I don't 10 know. And that's a big, big problem and 11 I think trying to get that message across that 12 13 you are responsible for a population of patients that are registered with you and you 14 really have to know what's going on with all 15 of them and have to reach out to them in some 16 way, that would make I think, may make one of 17 the bigger differences on population health. 18 19 CO-CHAIR HOMER: And again, 20 because the audience for NQF is broad and may of the users are plans who actually do have a 21 22 defined population and efficient practices,

1 but it's good. Lee?

2	MS. PARTRIDGE: I'm just feeling a
3	little confused. Are we talking in the
4	population health context of inviting outcome
5	measures be submitted for our consideration
6	that are things like incidents of carries
7	among of children under the age of 12, is
8	that what we're talking about? Because we get
9	I think we're going to get a lot. Well,
10	whatever.
11	CO-CHAIR HOMER: I said then that
12	will slide us very quickly to the Healthy
13	People 2020.
14	MS. PARTRIDGE: Well yes, it kind
15	of looks like that. And yet I absolutely
16	appreciate the relevance of some of that kind
17	of data for galvanizing activity in the health
18	community and in the community at large.
19	I mean I picked the dental one
20	because it happens to be a very difficult one
21	with respect to low income populations. And
22	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?

5 DR. WINKLER: Well ultimately 6 that's the question we're posing to you and as 7 Lee mentioned, if we don't put reasonable boundaries, we're getting more than we can 8 9 handle. So trying to find where those reasonable boundaries are for the work and the 10 people and us to do in the time frame is the 11 realities we have to deal with. 12

13 There's a lot -- there are tons of 14 things you can do, but the question is how do we define it in a way that is appropriate, but 15 doable. And so I'm not the one to answer that 16 17 Lee, you are. But it's a very appropriate question to put out for folks to consider to 18 help us define where the edges are, where the 19 20 boundaries are.

21 CO-CHAIR HOMER: So what I'd like22 to do is to call for break and give us a 15

minute break. Let you mull on these as well 1 as return a few phone calls and use the 2 facilities. We'll return in 15 minutes and 3 4 then try to come to some level of closure 5 around this topic. 6 (Whereupon, the foregoing matter 7 went off the record at 3:14 p.m. and went back on the record at 8 9 3:44 p.m.) 10 CO-CHAIR HOMER: Well we gave you a little more time during the break so that 11 you could figure out all the answers in your 12 13 small group discussions and come back to the group with it. Again, my sense from the 14 previous discussion was productive and broad 15 ranging conversation. 16 I detected a fair amount of 17 enthusiasm at one level for considering broad 18 measures of population impact with an 19 undercurrent of anxiety about both the 20 21 accountability and the flood gates that that 22 could open in terms of the response. That's

kind of my take on that conversation. 1 So I think what we need to do is 2 come to some closure in the next 45 minutes or 3 so with what we would like -- what we'd really 4 5 like to put as the scope of the call for measures. 6 7 And one thing maybe to start with, was it -- who had said they had in their mind 8 9 a multi-dimensional matrix? 10 CO-CHAIR WEISS: Donna. 11 CO-CHAIR HOMER: Donna. Did you -12 13 DR. WINKLER: 3D. CO-CHAIR HOMER: 3D, would you 14 like to start without putting you on the spot, 15 would you like to start by framing that up? 16 DR. PERSAUD: So I'm drawing over 17 here in looking at Bonnie's slides. I guess 18 what I'm kind of thinking is that growth and 19 20 development might be the permeating concept 21 across many measures. 22 And I'm starting with this one

sentence in one of the early documents that 1 says in the most global sense that a child --2 a health child is one who has transitioned 3 well from fetus to adulthood. And I like that 4 5 transition because I think that that's very foundational for pediatrics. 6 7 That's what the development defines as separate than all other speciality 8 9 lines, probably development and family. 10 And so I'm thinking that I would 11 like to have growth and development somehow permeate through all the measures, at least on 12 13 an assessment level that when we're looking at them we're in or out; are you, you know, does 14 this measure for ADD, for asthma where's 15 16 growth and development. So that's sort of one trajectory 17 going on. And then the other is that there's 18 growth and development one way, but at any 19 20 point while you're growing, whatever's going on around you in the environment is affecting 21 22 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.

9 And the last point I have in my 10 head is that let's maybe not try to be perfect, but come up with something that we 11 think makes best sense that we can all live 12 13 with, but that is somewhat forward thinking and might help to move the profession forward 14 in terms of being able to accept and deal with 15 the complexity because I think that in part 16 what's going on. 17

18 There's a depth of growth and 19 development and then there are the snapshots 20 going on of what is the context of the 21 community and the individual versus 22 population. So, I think after I sleep on it

I might have some kind of drawing. But that's
 my thought.

CO-CHAIR HOMER: 3 Any other thoughts how to build on that? 4 Tom? 5 DR. MCINERNY: Well I think it's always a good idea to sort of think about who 6 7 our audience or customers and I guess certainly HHS and CMS would be kind of the 8 9 national level and then I think about health 10 plans, the insurers or health systems, again, going down one more level and then eventually 11 down to providers, you know, provider systems, 12 13 practices, which is a smaller level. All of those people will 14 presumably -- the measures will be -- they 15 will be applied to them or they may wan to use 16 the measures one way or the other. And so we 17 need to think about making measures that are 18 useful at those various levels. 19 20 CO-CHAIR HOMER: Agreed. So the -21 - I wouldn't say tension, but I love the idea 22 that we're going to move things forward and be

1 forward looking. I think we should also 2 realize that for this to be picked up and used 3 probably should build on some of the 4 reasonably successful frameworks that are out 5 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.

1	I think we shouldn't shy away I
2	mean from an age based I mean the easy way
3	to force the capture of developmental issues
4	is to say deal with age and again it makes
5	sense to at least get people to think about
6	measures and basically the usual categories.
7	I mean, infancy, preschool and we can argue.
8	But, you know, base is zero, one,
9	you know two to five, school age which is 6 to
10	12 more or less and then adolescence, which is
11	13 to I better say 21 or the AAP and NACHRI
12	and all those other people will shoot me. So
13	we should write the AAP certainly. Those
14	would be reasonable things to do.
15	We need this developmental
16	context. I mean before I saw your list of
17	outcomes, I mean I was in clinical, functional
18	experience of care and then developmental with
19	the usual cognitive, emotional, social and
20	physiologic characteristics.
21	So those are lots of dimensions,
22	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 3 about and I keep thinking back a little bit to 4 5 some of Bonnie's slides if in terms of an overall depiction there was some slide where 6 7 there was the community, contextual, the big cloud with all the complexity and then the 8 9 blue got like a little bluer and it kind of 10 focused down more towards the health care 11 component.

12 And that was a good one too, but 13 the combination of the triangle one plus the 14 cloud one, but that one --

15 CO-CHAIR HOMER: The chronic care 16 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 multidimensional WHO definition of health or something comprehensive.

8 And then for the health care 9 system, ask explicitly for measures related to 10 child health that have a high component of 11 actionability and attribution by the health 12 care delivery system.

13 And then I'll go back to what I said before which is we have found, and I must 14 say one of my colleagues kind of put this 15 forward how incredibly helpful it's been to 16 use the Institute of Medicine six steps 17 towards high quality care. It's just worked 18 way better than I ever thought it would to 19 20 hang the ornaments on the tree.

21 But just so you know what we found 22 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.

5 CO-CHAIR HOMER: And I was just 6 going to say, the National Quality Report 7 certainly uses those dimensions matrix with 8 basically ***3:54:32 and the fact, you know, 9 living with illness, getting better, staying 10 healthy, end of life care framework.

So I think that for the health 11 care setting with a developmental context I 12 13 think would probably work reasonably well. I personally like your idea of soliciting that 14 as a distinct -- right, soliciting both but 15 articulating it as a distinct call or a 16 distinct component of the call and considering 17 those kind of as a group. 18 Two, sort of more 19 DR. WINKLER: 20 two types of things to differentiate them so that people don't get muddled. 21

22 MS. PARTRIDGE: But Reva, where

the developer can point to specific links 1 between the two, that will certainly 2 strengthen their position vis-a-vis our 3 judgement, right? 4 5 DR. WINKLER: In terms of the population measures, I mean we're still 6 7 talking the context of outcomes, right? Yes, okay, just making sure. Just checking. 8 Let's 9 not range too far, there's only five of us. 10 DR. BURSTIN: I just want to make 11 one other point actually just to give you 12 some, perhaps some comfort. When the measures 13 actually come to us they all have to complete, and Kathy knows this, a very detailed measure 14 submission form. 15 16 And so they're going to already have to up front indicate the level of 17 measurement or analysis for the measure. 18 And so that could be individual clinician, 19 facility, intermediary delivery system, health 20 21 plan or community or population. 22 So just to keep your mind -- so

1 there may be measures that will come in that 2 will be very appropriate or community population level like those preventable 3 4 quality indicators we endorsed through AHRQ, 5 but there may be some that would fit better at the clinician level. 6 7 So you can have the wide range and specifically indicate that this level of 8 9 analysis can be a very important consideration for the steering committee as those measures 10 come forward. 11 12 CO-CHAIR HOMER: And the 13 importance criteria specify the link to the --I mean they will have to at least articulate 14 how there's a link between health care 15 delivery and broader outcomes. 16 DR. RAO: Reva, just a question. 17 In the past for measures have individual 18 clinicians just submitted measures even if 19 20 they're not affiliated with the organizations? DR. WINKLER: Yes, it's not he 21 22 most usual, but yes occasionally, often

academics. Kathy are you an individual when
 you submitted yours?

3 DR. JENKINS: We submitted on 4 behalf of Children's Hospital Program for 5 Patient Safety and Quality. But I do know 6 that other people have just worked hard to 7 make a good definition and send it in. I 8 don't know how it's been received at NOF.

DR. WINKLER: 9 It's not the most 10 common, but certainly there's no reason not to do that if you know somebody who's doing some 11 good work. What we're planning on doing is 12 13 all the things you've brought up today, we're actually going to spend the rest of the 14 evening looking for some of this stuff, we're 15 going to bring it back to you tomorrow. 16

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

1 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.

8 One of the problems is, the only 9 way we can display it is two-dimensionally so 10 we might have to think creatively and sort of 11 in your mind build the third dimension or the 12 fourth dimension or whatever dimension you're 13 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 1 sounded good but didn't really look so good 2 now, can you do this, that or the other thing. 3 4 So it's a working together to get 5 some of your immediate feedback. But we will be looking to draft the call for measures, you 6 7 know, the meat of that and as well as this sort of framework idea of creating a way to 8 9 describe what we're looking for in child health outcomes. 10 And we'll use as examples the 11 12 existing endorsed measures to plug in there 13 and ask, you know, is this working, plus the idea of let's flag the population health 14 measures, we can see if we can do that, we can 15 give them a gold star or something and see if 16 we can put some of these into play and see if 17 this is working for you. 18 19 If not, we can, you know, we can 20 go to plan B or something. So what you've 21 done today actually has given us the tools to 22 try and synthesize it a bit to present to you

tomorrow to allow you to refine it, revise it, 1 scrap it and start over, whatever it is that 2 works for you as part of this entire process 3 4 of you guys being able to present this not 5 only to yourselves, but to a greater audience to understand how an approach for looking and 6 7 measuring child health outcomes. So questions about where we're 8 9 going? 10 CO-CHAIR WEISS: I have one quick 11 Tomorrow when you present to us question. 12 Reva, is it your thought that you would lay 13 out kind of a draft of the call for measures, is that the idea? 14 15 DR. WINKLER: Certainly the meat of it, you know, there's all sort of 16 boilerplate that goes fore and aft, but yes, 17 the actual we are looking for measures that. 18 19 CO-CHAIR WEISS: Right. I've qot 20 sort of two suggestions that I just want to 21 offer up and they just may be redundant to 22 what you're thinking already, in case not.

The first is to make it abundantly clear in 1 2 the title that outcomes is the focus and then to define right up front what we mean by 3 outcomes or whatever you think needs to be 4 5 taken into account in making that judgement call. 6 7 DR. WINKLER: Okay. Other suggestions? Now's -- jump in. 8 9 DR. MCINERNY: More of a question. 10 When you send out the call for measures, 11 typically from what organizations do you get 12 responses? 13 DR. WINKLER: It really is across 14 the board. I think this summer we pulled together all the measure developers who've 15 16 submitted measures over the years, we're trying to update their information on how --17 and working with us. 18 And it's over 75 organizations 19 20 that are currently on our list, but we know there are others, especially in specialty 21 22 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,

8 who else is doing them, STS has been a lot of 9 our measures, CMSs, NACHRI has done some, I 10 mean, you know, AHRQ, those are the big ones.

11 But we've had some, I mean like 12 Charlie said, he's got one of the measures on 13 BMI is from NICHQ and so sometimes it's only 14 one or two measures from an individual 15 developer.

16 So, you know, it's across the 17 board, but we're always looking to increase 18 our list so that whenever we put out a call, 19 we send it to that group as well, and you 20 know, we just want to keep building that list 21 to stay in touch with all the folks out there 22 who could be in the measure development

1 business.

2	DR. SCHWALENSTOCKER: Reva, I
3	think sometimes I've seen you put sort of an
4	advance notice that you'll be putting out a
5	call for measures, and I just wonder if that
б	might be an option here
7	DR. WINKLER: Yes.
8	DR. SCHWALENSTOCKER: thinking
9	about these might be harder measures to find.
10	DR. WINKLER: Well, yes actually
11	it's become fairly recently, but part of the
12	process to issue an intent kind of call, sort
13	of a flagging, yoohoo out there we're doing
14	this and ask them to just send in the list so
15	we have a sense of what we're working with,
16	you know, to give us some sort of forewarning.
17	We're only getting a fraction of
18	the ones that actually end up being submitted.
19	I mean we ended up with 14 on the intent for
20	the main call and we got 50 measures
21	submitted.
22	So, you know, but you're right.

To the degree that we can, you know, broadcast 1 this information and we're due to issue that 2 intent in December, it's got to be. So we'll 3 be doing that. 4 5 DR. SCHWALENSTOCKER: Yes, I'm just thinking it may not be so much that 6 7 you'll get that initial list, but you get --DR. WINKLER: But the information 8 9 is out. 10 DR. SCHWALENSTOCKER: -- people 11 thinking ahead of time and a chance for us to use, you know, whatever vehicles we have to 12 13 disseminate information, repeated messages. So it might be a way to go. 14 15 DR. WINKLER: Yes, no that's 16 Thanks Ellen. Absolutely. great. Is risk adjustment 17 DR. CLARKE: part of the submission if appropriate? 18 19 DR. WINKLER: Yes. 20 CO-CHAIR HOMER: Yes. 21 DR. WINKLER: Absolutely. Kathy's 22 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.

5 The way we've got it set up is 6 with the electronic submission now it merges 7 into the evaluation form, and we'll bring you 8 an example of the evaluation form that you're 9 going to see and it sort of sidebars where you 10 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

22 framework that I could think of that might be

helpful to make, I don't know, but to make the 1 link between these population based measures 2 and the actionable by the health care system 3 4 measures is I think something that IHI has 5 developed. I saw Maureen. 6 CO-CHAIR HOMER: The triple aim 7 framework? DR. JENKINS: I'm thinking, you 8 9 tell me because I saw it awhile ago, it's just 10 always been in my mind, about moving the big dots and that one of the ways to move the big 11 dots is to have everyone know what the big 12 13 dots are and then basically elaborate precisely how their actions will contribute to 14 moving the big dots. 15 In this case obviously to what 16 extent do the population health measures be 17 able to be moved through action through the 18 health care system is the obvious link, but 19 for the community or other groups that might 20 21 also want to move those population health ones 22 that could be helpful. It's not ringing a

1 bell?

2 CO-CHAIR HOMER: No, it absolutely3 is ringing a bell.

4 DR. JENKINS: It was a whole talk 5 on how do you move the big dots and strategies 6 to do that, it's really about alignment.

7 CO-CHAIR HOMER: Yes, it's about 8 alignment. So again it's just -- I mean the 9 idea in part is how to move quality 10 improvement away from doing these small 11 isolated cool little projects to having a 12 strategic aim and aligning your projects with 13 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.

19 It's sort of a logic model, but 20 the idea is those are each the drivers that if 21 you -- the ones to the right are basically the 22 small dots, the small activities that would

1 then lead to the larger dots.

2 So I do think that that would be a useful way for us to -- could be a way to 3 actually graphically present either in the 4 5 call for proposals or help us organize when we 6 get these things in. 7 If this is the outcome we want to achieve, which is perhaps kids being healthy 8 9 and ready to work and live and things like 10 that, and what would be the different components that would lead us to getting 11 there, which could include the community 12 13 outcomes and the clinical -- I mean I'm just thinking off the top of my head. 14 So I think that's the connection 15 between the big dot, the driver diagram and 16 where we are here. It's good. I can send you 17 the slides with the big dots. 18 19 CO-CHAIR WEISS: The one thing 20 that we haven't brought into the equation here 21 though is the earlier point that you made, 22 Charlie, about the education performance of

Page 299 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

13 terms of how a particular measure can be used 14 to evaluate health care performance? 15 DR. WINKLER: Typically NQF does 16 not get into that very deeply. In terms of 17 the implications on potential use as it 18 influences how you evaluate the measure, we 19 can't draw hardline on it because a lot of the 20 evaluation is around feasability and 21 22 usability.

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1	So you can't totally disassociate,
2	but we have no control over how it actually is
3	used. Recommendations that go along with it,
4	sure. Leverage, not a lot necessarily. But
5	if you think they're important aspects, and I
6	think the one that could be particularly
7	useful is reinforcing the level of analysis
8	for which the measure was developed and
9	intended to be used.
10	Again, we have no control over
11	what goes on out there, but making that clear
12	that you're evaluating it for use at, it's
13	only going to be used this measure is only
14	good at the health plan level or for
15	sufficient populations of a large enough size,
16	blah, blah, blah and isn't intended for
17	smaller levels of lower levels of analysis
18	or smaller populations, you know.
19	I think to state that is very
20	reasonable because you've done the evaluation
21	of its technical merits and a lot of this is
22	the technical aspect of sample size and all of

1 that.

2	So to that degree I think it's
3	reasonable to make those comments, but there
4	is just, you know, these measures get used in
5	a whole wide variety of fashions so we can't -
6	- and I think that's part of the something
7	to keep in mind is NQF endorsed measures are
8	used in a variety of ways.
9	But typically on the high level of
10	accountability whether it's publishing it on
11	a website or in a payment incentive program or
12	in a, you know, who's in and who's out of a
13	network situation. So significant levels.
14	So you want to keep that, that
15	that's what we're doing when you're evaluating
16	the measures. And so that's why we do want
17	them to meet the criteria to a significantly
18	good degree. The stakes are high, we know
19	that.
20	CO-CHAIR HOMER: Tom?
21	DR. MCINERNY: I'm wearing a
22	couple of other hats for the AAP. One, you

know, we're finishing up our mental health 1 project for primary care, we have a mental 2 health taskforce, we're going to publish a 3 toolkit sometime in probably mid-2010 I hope, 4 5 it's closing in on being finalized. 6 And the goal is to try to get 7 primary care pediatricians to be more comfortable with, to be more knowledgeable 8 9 about identifying and treating mild to 10 moderate mental health problems in children because there just aren't enough mental health 11 12 specialists to go around and we all know that 13 a small percentage of kids get mental health care who need it. 14 And I don't know when we're doing 15 the call for measures if we could specifically 16 kind of look for some outcome measures for 17 how, particularly one of the things we're 18 looking for is for primary care pediatricians 19 20 to collaborate with mental health providers, 21 and are there some measures that look at that

22 that lead to better outcomes.

1 I don't know, but that's one thing 2 that I think is important, and again need to dovetail that with the mental health group 3 that NQF has. Because it's, I mean clearly 4 5 it's the new morbidity and, you know, we know that it's close to 20 percent of kids have 6 7 some kind of mental health problem and that's far bigger than most anything else you can 8 9 think of. And then the other area that's --10 11 CO-CHAIR HOMER: So let me maybe 12 respond to that because I'm sure I'll forget. 13 So one thought is to make sure that when we put out the call that we specify, if we use 14 something like the acute chronic preventive 15 frameworks something like that in there is 16 that we include mental health. 17 So I think we need to explicitly 18 include mental health in that and flag it. I 19 20 personally think that something like -- and this relates to the care coordination 21 22 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 4 5 child mental health status or functional status or family functioning or something 6 7 along those lines would be my inclination. DR. JENKINS: or cost. 8 9 CO-CHAIR HOMER: Or cost, yes. 10 But we heard that cost was only quasi within 11 our jurisdiction here. So that was your other half of your question, I hope I didn't derail 12 13 you.

Yes, the other is 14 DR. MCINERNY: the other MH and that is the medical home and 15 that's clearly not a big resurgent -- big all 16 of the sudden interest at least and what's 17 bothersome to me is the pediatrician is at --18 almost everything you hear about these days is 19 20 with family physicians and internists and pediatricians who invented the medical home 21 22 are being left out left and right.

1	There's not very much going on in
2	that and actually we're putting together an
3	EQIP module on the medical on helping
4	pediatricians to, you know, make their
5	practice into a good medical home. And again,
6	you know, what measures do we have, outcome
7	measures that indicate that, you know, if
8	you've done all this work, how do you know
9	it's really working?
10	CO-CHAIR HOMER: Again I care a
11	lot about this topic, I wrote the background
12	paper for the AHRQ committee on basically the
13	medical home, it was framed in the legislation
14	as the most integrated health care setting.
15	But again, that's, I mean the
16	existing measures of medical home as you know
17	are largely structural never mind process and
18	there are some patient experience, reports of
19	those processes.
20	But I guess I would say what we
21	would want in this one, again if we were to
22	even mention it in the call it would be

something that would capture the desired 1 2 outcomes of a medical home, but they should be captured by the other things that we're 3 talking about, I would think satisfaction, 4 5 cost --6 CO-CHAIR WEISS: Care 7 coordination. CO-CHAIR HOMER: -- care 8 9 coordination outcomes. So maybe care -- but 10 again outcomes. 11 DR. MCINERNY: Apparently 12 ***4:14:49. 13 CO-CHAIR HOMER: Yes. DR. WINKLER: However, would it 14 really be particularly bad to include as some 15 of the desirable things or desirable outcomes 16 would be measures of the effectiveness of care 17 coordination or the medical home, I mean just 18 to be explicit? 19 20 CO-CHAIR HOMER: No, I think you should mention it. I think it's such an 21 22 important trend right now and something, yes,

1 I think it's a good thing.

2	DR. DOCHERTY: And speaking along
3	the lines of our areas or the hats we're
4	wearing that we want to make sure, and I think
5	it's covered in this conceptual model, but you
6	know, when I think about hospitalized children
7	and I know that that's if we're talking
8	about numbers of affected, this is a lower
9	amount.
10	But when I think about children
11	that are left in hospitals today, those are
12	very sick of the sickest. And more than of
13	children that die, more than 50 percent of
14	them, unlike adults, die in the hospital.
15	And so palliative care services is
16	one thing that children's hospitals struggle
17	with. And so, I was keeping my eye out for it
18	today, you know, and I think that the way we
19	measure whether or not children got good
20	quality of life care/palliative care is sort
21	of the through the parent satisfaction, long
22	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.

4 So I just wanted to make sure that 5 if when we put out the call that we had sort 6 of tweaked the eyes of those people that can 7 measure that kind of thing in parent 8 satisfaction.

9 DR. WINKLER: NQF has actually 10 endorsed a survey a families about end of life 11 care. The question is, does it capture kids? 12 It does, okay. It's just something -- I'm 13 not sure it ended up on our list. Now that I 14 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

21 following up on Marina's question to me
22 earlier about for example the school

1 performance. So, I guess to me that kind of 2 measure falls into two areas, one are these 3 broad community health measures, which is what 4 we want.

5 But there will be people submitting measures I think on, for example, 6 7 asthma. And I would want the people who are submitting the asthma related measures or 8 9 other conditions to think broadly in that 10 about outcomes that may occur outside the immediate health care context, which would --11 so I think we'd want to pick that up in two 12 13 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.

21 And I think I speak for Marina in 22 saying how much we're looking forward to

1 working with you over the next -- how long is
2 our duration by the way? Do we have a
3 timeline?

DR. WINKLER: Yes, you do have a 4 5 timeline. As I mention, we'll be doing a call for measures over the winter and you'll meet 6 7 again in April to formulate your recommendations and that will start the rest 8 9 of the consensus process. 10 So we'll be friends fairly closely through at least the first half of 2010 and 11 the project will end, I believe it's October 12 13 in final endorsement. And so we'll keep in touch with you on that. But so the active 14 work will be in the next, you know, six to 15 nine months. 16 CO-CHAIR HOMER: That will be 17 So looking forward to working closely 18 great. with all of you. Allan? 19 20 DR. LIEBERTHAL: Before we finish, 21 for those of you --22 DR. WINKLER: Use your microhphone.

1 This actually is DR. LIEBERTHAL: 2 not on the topic that needs to be recorded. For those of you who came in today may not be 3 aware the restaurant in the hotel is not open 4 5 for dinner. So I wanted to find out if people wanted to go find a restaurant. 6 7 DR. WINKLER: And in fact what we did, because a couple of you asked, is Ashley 8 9 has out front a list of restaurants in the 10 area. This actually in the area around Dupont Circle there are an awful lot of really 11 interesting small ethnic restaurants so 12 13 there's a lot. But the list is rather extensive, 14 they've starred a couple they think are grand 15 and we very much encourage you to explore and 16 even though it's rainy out there, you're 17 pretty close to a couple of really nice ones. 18 So the list is out on the front table that 19 20 Ashley has for you. 21 I think we're starting at 9:00 tomorrow morning. There will, I think coffee 22

starts at 8:30, yes. And so our morning, we 1 2 may finish more around noon-ish. We'll have to kind of see, you guys tend to be a bit 3 efficient. 4 5 But we've talked about what the 6 plan is for tomorrow, we're going to talk a 7 little bit about, you know, how to -- not only what does the call for measures say, but who 8 9 do we send it to. And then we'll talk a little bit 10 11 more about the measure evaluation process so that you'll have an idea of what's to be 12 13 expected the next time we actually meet in person, though I do anticipate we'll have a 14 conference call or two before that to keep you 15 up to date on what's going on. 16 And once we have a better handle 17 on the response to the call for measures, see 18 how good we were, we'll know what the work 19 20 plan is a little bit more detailed. So any questions for anybody? 21 22 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.

5 DR. BURSTIN: I'll just add that 6 we also will look towards you to tell us where 7 there are some good measures. So we don't often get just what comes in over the transom. 8 9 Actually, a good number of those measures and 10 the larger outcome, the adult outcomes committee came because of lots of sort of shoe 11 12 leather work on the part of the steering 13 committee and us.

14 So let us know if you know there's 15 some good pockets of measures out there. For 16 example, going back to your point earlier, 17 measure developers who wouldn't otherwise 18 think to submit to NQF, please let us know. 19 We're happy to sort of the queue them to get 20 them in.

21 (Whereupon, the foregoing matter22 went off the record at 4:21 p.m.)

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