# NATIONAL QUALITY FORUM

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# PERSON-CENTERED CARE AND OUTCOMES COMMITTEE MEETING

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TUESDAY
APRIL 8, 2014

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The Committee met at the National Quality Forum, 9th Floor Conference Room, 1030 15th Street, N.W., Washington, D.C., at 8:30 a.m., Sally Okun, Co-Chair, presiding.

PRESENT:

SALLY OKUN, RN (Co-Chair)
    PatientsLikeMe
ETHAN BASCH, MD, MSc, University of North
    Carolina at Chapel Hill
MAUREEN CONNOR, RN, MPH Institute for
    Patient-and-Family-Centered Care
DAVE DEBRONKART, JR.,Society for
    Participatory Medicine
JOYCE DUBOW, MUP, AARP
JENNIFER EAMES-HUFF, MPH, Consumer-Purchaser
    Disclosure Project
TROY FIESINGER, MD, Memorial Family Medicine
    Residency
LORI FRANK, PhD, Patient-Centered Outcomes
    Research Institute
CILLE KENNEDY, PhD, ASPE
KEVIN LARSEN, MD, Office of the National
    Coordinator
LISA LATTS, MD, MSPH, MBA, FACP
    LML Health Solutions, LLC (via
    teleconference)
BRUCE LEFF, MD, Johns Hopkins University
    School of Medicine
MICHAEL LEPORE, PhD, Planetree

PRESENT: (Continued)
MARY MACDONALD, MS, BA, American Federation of Teachers
ELLEN MAKAR, MSN, RN-BC, CPHIMS, CCM, CENP, Office of the National Coordinator for Health IT
EUGENE NELSON, MPH, Dsc, Dartmouth Institute for Health Policy and Clinical Practice
MARK NYMAN, MD, FACP, Mayo Clinic
LAUREL RADWIN, RN, PhD, Veterans Administration
ANNE WALLING, MD, PhD, University of California-Los Angeles
JENNIFER WOLFF, PhD, Johns Hopkins Bloomberg School of Public Health

NQF STAFF:

KAREN ADAMS
MITRA GHAZINOUR
KAREN PACE
WENDY PRINS

## T-A-B-L-E O-F C-O-N-T-E-N-T-S

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

8:36 a.m.

MS. PACE: Okay. I think we'll go ahead and get started. And, operator, you can get us started.

OPERATOR: Welcome to the conference. Please note today's call is being recorded. Committee members, you will have an open line for the duration of the call. Please do not put your line on hold. Please stand by.

MS. PACE: Okay. Good morning, everyone, and welcome back. Thank you for all your hard work yesterday. I know there was a lot of great discussion and ideas flowing, so we'll be sharing those today. And I'm going to turn it over to Sally for a few opening remarks. We're kind of adjusting the agenda on the fly, but we're flexible.

So, Sally, I'll let you start.

CO-CHAIR OKUN: Okay. Well, thanks everyone for coming back and joining us today. I think a lot of good work got done yesterday in the individual groups and I think what we're going to hope for today is that we're going to use much of the morning today to sort of do the recap of the individual groups. So each group will have a chance to present the concept.

We're going to provide a little opportunity for discussion after the presentation and then a couple of parking lot kinds of things. You know, sort of giving the group an opportunity to identify is there anything that's glaringly missing? Is there something that maybe doesn't belong? And then really start to articulate does this look like a short or a long-term objective that we can be working towards? So we're going to do some of the work that we had sort of plotted out to do separately throughout the day sort of as an integrated process. And that seems like it would be a better approach.

And then the other thing I'd like

to sort of suggest, because, you know, so much of what we're working on here is thinking about these from the perspective of persons and families and what does that look like when you're thinking about person and family-centered care?  So I think we all need to put on the lens of being a person in a family and as we're looking at it not only be thinking about it from the perspective would this matter to me?

We heard a lot of that yesterday, a lot of people talking about their own personal experiences.  And sometimes when we come to these exercises, we start putting our professional hats on and they sort of cloud our ability to really look at it from the personal perspective.  So I think we really need to look at it from both.  Start thinking about how does this feel for me if I were being measured on this as a clinician or whatever if you're representing a constituency group.  But then also how does to feel for me if I'm at the clinical level or if I'm at the point of care? How might this operationalize? How might it look to me? And would it mater to me? And I think those are the very key important questions.

So I think that's about all I need to say other than I'm looking forward to this morning. I think it's going to be an exciting opportunity. And I can see that there are some groups that actually take things really seriously and come back with a really nice presentation here. So thanks for that.

We're looking forward to it. It will great. And I think it just demonstrates how we communicate and we work on things differently. Each group takes a different approach and we have different ways of thinking through different problems. So it's going to be a great exercise. Thank you.

MS. PACE: Okay. So I'm going to go over just -- well, we'll show you here. Okay. So we've totally adjusted our agenda for today.  So I'm going to do just a little overview of priorities for filling performance measure gaps so that we can be thinking about that as we're going through the presentations from the groups.  And then as Sally said, we'll really spend all the time we need to get through all of the discussion.  We will take a break and we'll see if there's any public that want to make comment.  We'll have lunch at 12:30.  And then we'll reconvene and again see where we're at, take a pulse and see what we need to do.  But we can also talk about if there are additional recommendations outside of the specific measure concepts.

So we talked a little bit about this yesterday, but just to have it at the top of your mind; Sally's already mentioned a few things to kind of think about these as we're discussing them through the lens as a patient and if you're a provider as well, but some priority considerations.

You know, I talked about yesterday

in terms of measure concepts.  We really want to focus on the most important things.  And rather than getting into the technical details of our criteria, I think the kind of high-level question is is it something that when we're talking about a national performance measure standard that all should do in the same way?  So, you know, it's going to be standardized and everyone should do it.  So we need to think about it -- or for a particular group of patients or a particular setting, you know, to kind of think of does it rise to the level of being a national standard that we want everyone to invest in infrastructure and processes to do?

The other considerations.  First and foremost is meaningful to consumers, and hopefully with the measure developers eventually will be built with consumers focused on the entire care experience.  And we spent a lot of time yesterday talking about the core concepts and that those really reflect the experience of person and family-centered care.  And certainly many of these things should be measured from the person's perspective.  And again, I think an overarching question for us to keep in mind is would the information from the measure be meaningful and useful to patients and consumers?  So I think if we just kind of keep those in mind, we'll be doing well.

The other thing we talked about is eventually kind of thinking of these in short-term versus longer-term recommendations.  And so, some considerations here is the readiness. Is it something that's already in clinical practice?  Are there are infrastructures to do it?  What's the resource and investment needed?  Other things.  But we may want to be thinking about these eventually as what's more short-term versus longer-term.

And the other thing is to just keep in mind -- and I don't know if you talked about it in your small groups, but something that we can continue to think about is whether any of these things lend themselves to the label idea for person and family-centered care.

Okay. So I think with that, we'll begin our report out from the small groups. And, you know, we'll ask you to summarize your discussion from the group. Basically we asked all the groups to come up with their top measure concepts and you had a work sheet to do that with. You know, so what is the structure process or outcome that should be measured? What patients should be included? If you know a data source, what would that be? Whose performance should be measured? You know, is this a system-level measure? Is it a population-level measure? Is it a provider-level measure? And again, anything that you identified that would be useful for the label concept and any other important themes that your group discussed.

So we can start with group 1 and I

think that's the handout you have, but group 1 was -- Gene Nelson was the leader and Ethan was in that group, Jennifer Eames-Huff and Priti. And is Priti on the line?

(No audible response.)

MS. PACE: She was going to try to join us through the conference call line.

But, Gene, I'll turn it over to you and you can proceed how you like.

MEMBER NELSON: Great. How much time would like us to take, 30 seconds or a whole minute?

(Laughter.)

MS. PACE: Oh, good question. We'll do one concept at a time. So let's do the first concept. We think if you would present all of the measure concepts first and then we'll have a discussion with the Full Committee.

MEMBER NELSON: Okay.

MS. PACE: And we're going to be flexible on time, so I guess we'll kind of try to keep track, but we've got, you know, basically the whole day to get -- I shouldn't say -- not the whole day, but until lunch time to get through all the groups.

MEMBER NELSON: Okay. And Ethan's going to be co-presenting. He's going to be the John Madden of the group, the color commentary. I wanted to do that, but he won.

MEMBER BASCH: All right. Gene is winding up now.

(Laughter.)

MEMBER NELSON: And Karen gave us these great notes, so thanks, Karen.

Under Concept No. 1, the whole person, we had four suggestions for measurement concepts. I'll just read those through quickly and then go into some of the details.

The first is seeing the patient as a whole person, for my care partners seeing me as a whole person.

The second is care centered on my

goals and preferences.  So my care is centered on my goals and preferences.

The third is systematic assessment of patient-reported outcomes and well-being.

And the fourth, which we don't have perhaps quite as much enthusiasm for, staff training and patient engagement was the general header.

Ethan?

MEMBER BASCH:  I don't have much to add.  Just going through, we debated about the first one, seeing the patient as a whole person because we felt this is a very important concept but is a challenging thing to measure.  And we spoke a little bit about whether this would be a patient-reported measure.  We talked about the concept of a whole person and whether that's actually measurable.  And we thought about the core components of being seen as a whole person and felt that potentially a measure developer could break that down into several discreet components for measurement, but we felt that this really was ideally suited for a patient-reported assessment probably with multiple assessments.

As far as care centered on goals and preferences, this was really a discussion around alignment of values with care that's delivered and preferences for decision making being in alignment with care that's delivered. This is kind of standard stuff out of the shared decision making literature and we felt that this was closely related.

The PRO piece we talked about yesterday. The systematic integration of patient-reported measures into routine care we felt was also essential to understanding the health status and the situation of the patient. And this could go beyond symptoms and functional status to other areas that are important to understanding the patient's own situation.

And then finally the staff

training. We were trying to channel Kevin a little bit here thinking about the very discreet measure of the time at the bedside. So we thought what are very discreet processes that we could potentially measure? And we felt that training all staff members who actually touch a patient at any given time during longitudinal care would be important to enlightening our colleagues.

Was that colorful enough, Gene?

MEMBER NELSON: Beautiful.

MEMBER BASCH: All right. Thank you.

MEMBER NELSON: With respect to the data sources and who should be measured, or the level of measurement, or the unit of analysis, for the first three we saw a role for patient reports being probably predominant with a possible process-style measure for the second and third, care centered on goals and preferences and systematic assessment of PROs and well being.

And then we in general said, well, if we thought about a cascading set of measures so that it might be at the health system or health plan level; so it might be Dartmouth-Hitchcock Health System or the health plan that Dartmouth runs, that might be one unit of analysis.

And the second level down might be a clinical program, sort of the meso-system level.  So people with cancer.  Women having babies.  People with diabetes.  And trying there to get a reflection of care more across the continuum but attributable to that population.

And then the third level, more the microlevel of the individual care unit or the individual practice, or in some cases the individual provider, down to that level.  So in general, we thought cascading measures that would come bottom-up or top-down in an organizational hierarchy.

CO-CHAIR OKUN:  So open it for

some discussion.  Kevin?

MEMBER LARSEN:  Yes.  Thank you. This is terrific work.  A couple of questions: So seeing the patient as a whole person.  I'm not familiar with CAHPS enough to know, is there anything at all like this in CAHPS?  And if not, is that the sort of place for something like this to go, or is this a different -- do you do this kind of interview in the clinic specifically to be different than the anonymous nature of CAHPS?

MEMBER NELSON:  Yes, we didn't talk about that extensively, but my sense is that as a general delivery vehicle many of the person-reported outcomes of experience that we're talking about here could be imbedded in a CAHPS system.  The CAHPS might be, you know, the reusable rocket that these tuned measure concepts might start to become part of.

MEMBER LARSEN:  And then a clarifying question about your PRO.  Is this kind of a process measure or a structure and process measure that says PROs are routinely available to be used in a clinic and PROs are routinely used, or is it something that you're actually -- is it some composite of a lot of different PRO outcomes?

MEMBER NELSON: Well, one image was that an individual would report, self-report. My physical health and well-being are taken into account, so that would be the patient-reported outcome, a PREM, patient report of experience measure.

But then another would be a process measure or a structural measure. For example, the Dartmouth-Hitchcock Spine Center does or does not routinely assess patient-reported outcomes as part of the care assessment and follow-up process.

MEMBER LARSEN: Yes, I mean, just to expand on this, this could be both having an EHR with the ability to collect PROs through a portal and then secondarily the proportion of patients who actively report and then maybe even the proportion of patients for whom a provider signs off on the electronic report in the EHR or something along those lines.

CO-CHAIR OKUN: I'm wondering a little -- and maybe you just addressed that, Ethan. So from a time perspective. So one of the things that I would want to expect would be if someone's going to be able to treat me as a whole person they know a little bit about that before I even arrive, right, versus waiting to get a survey afterwards to assess whether or not they actually did well.

So I think if we don't have some sort of time frame that says there's something that occurs at the institutional or the clinical level that suggests they're ready for me when I get there so that they know me as a whole person to the degree that they can, and then I can best measure that later. So that's almost like a short and a longer-term kind of perspective that maybe we can measure it in the post-experience. But then we need to back into how do we improve the pre-experience.

MEMBER DUBOW: I think most of these -- and you guys were obviously the A students in the class, but I had the same reaction. The only concerns I have is that I don't think people are going to respond. I don't think they're going to know what we mean by knowing me as a whole person. I think that's our jargon. And I think this is the only place where I might actually think about the meaningful use requirement for a family history being reported and referred to in advance as a means. I mean, it's a place where I think the process measure might help jigger people's understanding of what we mean, because I just worry that it's too inside baseball.

MEMBER NELSON: So I understand very well the point you're making, Joyce, and one image is we have a measure concept that, let's say, the people around this table and others might understand what we mean to get at and then to turn that into a measure that the regular individual would answer and answer in line with this concept that has been laid out. That's where the qualitative work happens. That's where the cognitive interviews happen. We mean to measure X in this population. We're using these funny descriptive words in our concept, but what words would you actually use that would make sense to the individual?

MEMBER DUBOW: And all I'm suggesting is that this may be a place where the process measures might guide both clinician and patient understanding of what we mean, because it's multifactorial, obviously. But, you know, the annoyance of people having to repeat medical histories a hundred times even if it's in the record, but, you know, the failure to refer to it, or the -- you know, as Sally points out, the lack of familiarity. You know, what are you here for? You know, the reading-the-record-as-you're-standing-there kind of thing. It just seems to me that we need to -- you know, sometimes a process helps a little bit. But again, I understand the testing part.

MEMBER NELSON: So my bias, if you will, is generally towards outcomes and patient-reported if it's reliable and understandable. And so this could flunk out in the reliable and understandable in the cognitive interview phase or it might go through with flying colors.

MEMBER BASCH: I mean what -- I'm sorry. Go ahead, Sally.

CO-CHAIR OKUN: I was just going to actually see if there was other comments, so go ahead, Ethan.

MEMBER BASCH: I was going to say I was a little bit interested in this last one, the staff training. And, you know, potentially one could embed in that sort of staff training in the tenets of patient-centered care delivery and one could actually specify what those tenets are.  And one of those could actually be, you know, not reading the chart for the first time in the presence of the patient and so on and give some guidance to what staff should be thinking about.

MEMBER LARSEN:  So as an educator, which I thought was going to be my long-term career, where we were moving was more in observation and feedback of behaviors.  So that the idea of training is great, but I think a lot of us feel, especially with the sort of push to adult learning theory, learn on your own time and in your own convenience over the Web, that what we really hope for is that a certain set of behaviors are happening. And the most effective way to know that is either to simulate them and do observation of simulation or to observe and give feedback in real life.

Now, those are both more expensive than the kind of easy Web-based training we do, but I would call out something in here that we would want it to be -- know that this is effective training that has been demonstrated to actually move the needle.

CO-CHAIR OKUN:  Yes, Troy?

MEMBER FIESINGER:  So I'll tag on that and add some comments.  I think training is important, but what my healthcare system would most likely do is call our vendor that does all the back pay and HIPAA compliance, et cetera, models that I do once a year, add that to it and I would be required to do it once a year or be locked out of the computer system.

(Laughter.)

MEMBER FIESINGER:  Because when we have 10,000 employees, that's how you get it done.  My concern would be the same as Kevin's.  The goal has considerable merit.  We would literally view it as a check box.  So while it should be done, my preference would be focus on the outcome, which is actually do it for the patient.

To get at No. 1, I like the whole person. We talk about that in family medicine all the time, but it's also our professional lingo and our educational lingo. But for those who aren't aware, the Accreditation Council on GME is requiring all resident programs to completely revise our curricula and focus on goals and outcomes. And we said, well, how do we know if someone is a good doctor? It's pretty hard. But the schema they have proposed for us is essentially five levels. Five would be greatest doctor ever. Zero, go back to medical school.

So if you're getting at whole person, one way to approach that might be vignettes. Because what we've been doing is we have examples of each level. Is that resident like X? So did they not ask you about your information ahead of time? Did they not have it? Or they had it. They knew me. They knew my sister's name. They knew that my dog is brown. And I'm being a little facetious, but you can have examples in your questionnaire to the patient to get a better feel for it and then at least quantitate it somewhat. Because it's muddy, but it's really important.

MS. PACE: I just wanted to kind of ask a question about the outcome measures. So for example, Joyce brought up about you need to do a history, you need to do the family history to understand the whole person. And this kind of piggybacks on what Ethan said yesterday, is that that's history and physical is part of most clinical practice, but people don't necessarily feel that they're getting person-centered care even though that's the history of medical practice, or clinical practice.

So I guess I'm going to keep pushing on this. If you were a patient or someone looking at quality performance measures and you had to measure what percentage of the patients had a comprehensive history and physical in their chart, would that give you confidence that that was an indicator of person and family-centered care?

So I think we need to keep coming back to, you know, what's going to be a meaningful indicator of person and family-centered care.  And it's going to be hard, because we know that these things should be done.  Just as Troy was saying, we know that training on these things may be useful, but again, you know, to have a structural measure, you know, does the organization provide training on this?  It's going to look like a check the box.

So I'm going to just keep challenging us to think that way because these are questions -- and Joyce knows this from our Consensus Standards Approval Committee, that these will come up if measures like these come forward.  Is this a checking off the box and does it really represent person and family-centered care?

CO-CHAIR OKUN: So we have a few cards up. And in the interest of time what I'm going to do is go around once and then we'll do a final sort of say if anybody's got some more comments, and then move on to the next one.

Laurie?

MEMBER RADWIN: So, you know, you assess the whole person so you can deliver individualized care. And so the test on a patient's level is did they know that my mother died early of cancer and now I've got a cancer diagnosis? And did they titrate their information, giving to me that way with that in mind? And, you know, when you look at what patients say in qualitative studies when it gets aggregated, essentially it falls into four buckets: What have I been through my experiences? What do you see in my behaviors now? You know, how do I feel about this and how do I perceive the meaning of the illness in this situation? And what you look for is are you giving standardized teaching to someone who has a low health literacy level?

So assessing the whole person is the beginning and you have to have domains of what a whole person is, and I think those domains are fine.  Again, we have some empiric literature to talk to us about what belongs. There's the, you know, Planetree assessment. And but the rubber hits the road in treating the whole person when you individualize, use that information to do something.

How you capture it electronically, I have to think about that, or in a measure. I think it's doable.  People know when they get individualized care.  You can ask them. You know, and there's questions on all kinds of individualized care assessments.  So that's my thought.

MEMBER DEBRONKART:  What's the timeline for a project like this?  Like after a meeting like this how many years into the future does the result show up in the field?

And the reason I'm asking is because when we talk about infrastructure are we talking about things that for instance EPIC might build into a system five years from now? I'm sure it wouldn't be next quarter? Is it like 10 years?

MS. PACE: Well, there's no specific timeline, and we'll ask Kevin to address -- I mean, you know, they're interested in this in terms of, you know, HHS letting out contracts for performance measure development, but I don't know the timeline exactly of that either. I mean, it can be short and it could be very long. It depends on the uptake.

MEMBER DEBRONKART: So projects like this in the past, like what's the shortest between a meeting like this and things being reality in the field? I can't believe it would be anything quicker than two years.

MS. PACE: Yes, I think that is

reasonable.

MEMBER DUBOW: But a lot of these concepts --

CO-CHAIR OKUN: If you're going to comment, we all need to hear you.

MEMBER DUBOW: I was just saying Kevin could talk about it. I mean, you know, so because it requires certification of the electronic record to be able to capture this stuff. So it is time consuming in terms of getting it in.

CO-CHAIR OKUN: Yes, and I think we've also identified that there are going to be some elements of the things that we are putting forth that could be potentially short-term because possibly there may be something that's already available for this to be able to be, you know, maximized and optimized. But then there may be some things that need to go through the whole measure development process and validation process. So I would suspect that we have some that could be shorter, but then other objectives that could be way longer.

MEMBER FRANK: Hi. So thank you for that. Appreciate it. I'm just wondering about the nature of the discussion of the group about the meaning of the concepts, you know, before we move on to actual measure domains and then items. I feel like I need to understand the concept deeply. And so, the idea of meaning of illness to the individual has been raised. Really important. The idea of appropriateness of the medical information available to the provider at the time of the visit. And it seems to me part of what is beneath this is are the providers taking a holistic view toward the patient's care?

And so I am just interested in what went on in your breakout group as you were talking about the meaning of the concepts represented by No. 1.

MEMBER BASCH: Are you referring to the first one specifically, the whole patient one?

MEMBER FRANK: Yes.

MEMBER BASCH: Gene, do you want to comment, or do you want me --

I think it's really challenging. Actually we had a fair amount of discussion and obviously in the short period of time we had to think about all the components, and whole patient I think was challenging. But I think that we agreed that it is a real concept and that it has to do with understanding the details of a person's life and the context of their life and the context of their illness. And we felt that that probably could be broken down into multiple components. And probably all would be along -- like my primary care team, you know, understands my home living situation, or something along those lines.

MEMBER FRANK: Well, although if you're talking about the sub-component of appropriate information, then, you know, there are process measures. Does the care team have all the information from medical visits in the last two years?

MEMBER BASCH:  Yes, Yes.  No, I agree, and I think that's actually I think what Karen was getting at was, you know, can you actually, you know, pull stuff out of the chart.  I think the concern that we had is that it's actually routine in an HPI that a physician does to include the social history, the family history, the habits, you know, all this stuff that traditionally was actually supposed to give us a holistic view of the patient.  But somehow we've lost that.  You know, despite that, you know, here we are.  So I think that was our reticence on that.  But I agree with you.  I think it's -- you know, maybe it's missing more than one might think. I don't know.

MEMBER MAKAR:  So just to address the earlier point, I think the whole idea of the timeline or this project is multifaceted. Part of it is to get the conversation going and get the direction moving. So I think, you know, if it takes awhile to actually get the measures, that that's not necessarily like the total end goal. Part of it is having this conversation and bringing it forward. So regulation is one of the levers that ONC has, but certainly we want to try to use other ones as well. And you would think with something like this it would be kind of do the right thing, right? Find a way to do the right thing.

So I think sometimes with measures it's not so much that you want to catch people, you know, or have a performance score that you can necessarily beat them with, right, but have something for them to understand and aspire to.

MEMBER LEFF: Yes, the whole person construct I think needs to be pushed a little bit. I think we understand it because it's part of our jargon and our lingo. I think it's not necessarily as clear to others.

And the thing I'm thinking about a little bit is, you know, we think of whole person. I'm wondering whether patients may think about this using different words.

So I'm reminded of Tom Lee of Partners and now at Press Ganey. He talks a lot about this notion of the importance of trust or love that a patient may have for his or her health system. And, you know, if you ask me, Bruce, do you trust your doctors, do you trust your care team, that might actually encompass some -- it may touch on this construct of whole person. It may touch on a lot of these things.

MEMBER WOLFF: So in the discussion today we've been talking about CAHPS and I just pulled up the CAHPS questions for cultural competency and there are numerous questions that touch on these domains about being respected, having the questions answered. Does the provider care as much as you do about your health? In the last 12 months did you feel this provider really cared about you as a person? So I think some of those questions already do now exist, which potentially is helpful in terms of thinking about next steps and not reworking the wheel.

MEMBER WALLING: I was just thinking about the denominator for some of these and how we think about the patients that have perhaps higher need, or you might be able to see more variation in the responses if you're only seeing your doctor once a year versus seeing your doctor regularly with a chronic illness or multi-member morbidity. And just from a measurement standpoint higher need patients might make a better denominator.

CO-CHAIR OKUN: Okay. I'm going to just throw a little provocation here. As I looked at this as a provider, I was wondering, well, how do I know enough about the person to know that I can treat them as a whole person if I'm going to be measured on that? And then I looked at it as a patient and a caregiver and said I need to take responsibility to tell someone who I am as a whole person. So I think there's again this sort of flip need here when we start looking at what whole person means. And I think to Bruce's point most people and patients, they're not going to know what that means. A lot of clinicians are not going to have this whole sort of sense either.

So I think if we're starting to think about where this could go, it does require, certainly in the development process, to find ways of being able to nuance what this does mean, but also then find places where some of it's already being measured. But I don't want to wait until after my visit for me to get asked those questions. So we need to push it forward.

If we're going to push it forward, then people need to take some responsibility for being able to trust who it is that's asking this information ahead of time and then be willing to provide it so that the whole person kind of sensibility can actually take place.  But that means that as a system we need to provide them appropriate tools to do that.

So I think there's a few things to lead into it that ultimately for it to actually occur and then to actually be measured afterward are going to have to come together it would seem.

Bruce?

MEMBER LEFF:  Just one last comment.  I think what you're saying also that triggered the thought in my mind that there are -- and I can think of many patients who would actively opt out of the notion of person-centered care.  And I think that's really something to keep in mind.  They don't want to be bothered.  They just want to come in and get the muffler changed and they want to move on.

MEMBER MAKAR:  But, Bruce,

honoring that, isn't that person-centered?

MEMBER LEFF: It is, but the way that we are talking about this feels very much like this will apply to all. And I think there are people who really -- they just want to get what they think of as healthcare.

MS. PACE: But I think what Ellen is saying is that that would be person-centered for that person.

MEMBER LEFF: Yes, it would, but it depends on -- you know, think about the construct. You will construct measures very, very differently.

MEMBER DEBRONKART: So what we may need as the foundation for this is essentially a patient preference profile like people have on other Web sites.

CO-CHAIR OKUN: And some of that again I think we're starting to leak into other concepts, too. So in the interest of time, I think maybe do people feel like we've discussed this one well enough for -- do you feel like you have -- because the other thing that we were going to do is just a little bit of a touch point.  Is there anything that's glaringly missing from the presentation on this particular concept?  And is there something within the concepts, the things that have been presented here, where we feel like it doesn't quite fit?  Any thoughts on that? Anything that's glaringly missing?

MEMBER FIESINGER:  Not missing as much as at the end are we going to back and look at how much overlap there is between different concepts and see if we can conglomerate?  Because there is a huge amount of spillover.  And I'm thinking, oh, there are a couple other concepts that address your exact point.

MS. PACE:  Right.  And actually what we want to do, which I didn't mention -- so this is what you have instead of like the individual sheets, right?  But what we'll do is put them up on the sheets back there.  And so for the other groups that are presenting, you know, have the individual sheets, we'll tape them up back there. And so we'll be able to maybe during one of the breaks and at lunch kind of start looking at that across the -- because you're right, there will be some overlap and we will need to look at that.

MEMBER FIESINGER: Just quickly, I thought of a humorous story along Bruce's point. When we did Press Ganey's surveys, one of my patients wrote a very angry letter to my boss saying how dare you question Dr. Fiesinger's ability as a doctor. He's wonderful. This survey sucks.

(Laughter.)

MEMBER FIESINGER: I think that was a positive evaluation.

CO-CHAIR OKUN: Well, we can survey people to death ultimately when you get down to it, so we do need to be careful about that.

Joyce?

MEMBER DUBOW: I just have a process question. Is there going to be a report that we're going to review before this goes anywhere? Because, you know, Bruce, if you read the sticky questions, the one right under No. 1, you know, my partner's ask about what my top health goal is. To tune up my muffler. What's important to me my muffler has to be fixed. My preferences are considered. I only want my muffler fixed. Integrated tools for assessing his preferences, whatever that one is. Sorry.

(Laughter.)

MEMBER DUBOW: But I mean --

MEMBER LEFF: But my preference may also be I don't want to talk about any of this other stuff at all. I don't even want to engage in it. I don't want to be asked about it. I don't want to touch it at all. Please, just give me the antibiotic for my strep throat and I want to move on.

MEMBER DUBOW: Okay. But I asked

the question because -- I mean, I understand what you're saying and I understand that you're worried about what the measure is going to look like, but I think that even determining that is, as you say, patient preference and patient-centered care therefore.  And so I hope that our report reflects that it could be a very minimalist view from an individual.  So I just wanted to know whether we're going to get a chance to see how this stuff is articulated.

MS. PACE:  Absolutely, because I think we'll need a lot of post-meeting feedback on where we end up.  I mean, you know, these meetings are great.  They generate lots of discussion, but we do have to kind of distill it and we'll definitely need your guidance and assistance with that.

CO-CHAIR OKUN:  I think the other thing that I noticed, too, on the sheet here there is a lot of nuance that's added in that were put on the stickies that we didn't actually go each one individually. And we have to trust that the group actually took some of that into consideration as we move forward.

So I think let's move on, if people are okay with that. Shall we move on to Concept 2? That's the same tag team over here.

MEMBER NELSON: Yes, and Jennifer has joined us. Hi, Jennifer.

So that was great discussion on Concept 1.

Concept 2, care I need, when, where and how I prefer. Four concepts. The first, a global measure really to the point of the concept. We'll come back to that. Second around convenience of communication. A third around convenience of scheduling. And the fourth around care coordination and interdisciplinary care.

Going back to the first one, the idea of having an overarching global measure for this aspect.  For example, I get everything I need exactly when I want and need it might be a PRO, or would be an example of that.  Or I did not receive unwanted care.  We fussed around with that quite a bit.

Then convenience of communication has to do with I can get my questions answered and I can get information in a way that's convenient for me.  And you'll see under the individual stickies some of the aspects of that that might be plumbed.

The third area convenience of scheduling I think goes to the point of when and where I prefer.

And then care coordination and interdisciplinary care, the idea that when needed a care team is taking care of me and also my care is coordinated.

Again, in terms of the ideas of what patients and sources of data and unit of analysis, sort of similar to the first.  In general thinking about this being useful at the whole system level and the clinical program or meso level and then the micro level in general. That was the thought. And some of these you'll see we thought were amenable to being either a process and a PRO or a structural measure and a PRO.

Ethan?

MEMBER BASCH: I was going to defer to Jennifer.

MEMBER EAMES-HUFF: Okay. So I think with this one for some of the discussion we were struggling a little bit with the care I need when I need it. So it got broken down into quite a few different components in terms of how to do it.

I think we felt like communication was a really important piece to this, but we weren't sure if some of these were overlapping with another domain. But we didn't want to lose sight of them, so we still included them. So we recognize somebody else may have them. And we thought also since we thought they were important that if somebody else also has them, it will show that this is something that really should be looked at.

And then, let me see if I should say anything else about it.

We did on this one also get into more of the -- I think more detailed in the measures than in the first one.  We got a little bit more nitty-gritty in some of what the process measures could be.  So that was a little bit different from the first one that we had done.

CO-CHAIR OKUN:  Troy?

MEMBER FIESINGER:  Okay.  I'll jump in.  So I was looking at communication and scheduling and I was thinking of how this would work in my practice.  So if you asked us, we could say we have a patient portal, we have email, we have telephone.  We don't have text yet.  So we're doing it.  But while those technical social matters or measures are important, what I really want to know is does the patient feel that we communicated with them in a convenient fashion?

And same thing with scheduling. I could tell you about 3rd available 30 day -- 30 minute visits, sorry. We have after hours. We have weekends, blah, blah, blah, blah, blah. Does the patient feel that we got to see them?

So as much as I don't want to say the answer is always patient survey, for me a lot of this what I want to know as a physician is is it working? It's customer service. So I think we really need both hard data, but does my 3rd available 30-minute visit of 5 days actually mean patients feel they can get in to see me or are they still ticked off that they, quote, "can't" get in to see you because you're on vacation, which is where I am now, in case you were wondering.

(Laughter.)

MEMBER LEFF: So when I read the draft concept "I receive the care I need, no more, no less," in my academic brain that sounded to me that the issue was there overuse/under use, right?  I don't know if it was, but the inference I drew under the global measure, the third individual sticky was, "I did not receive unwanted care."  So was that the way the group interpreted no more, no less?  Was that unwanted?  Because that to me feels like a very different construct.

So the no more, no less feels to me if you have the mole, you don't get sent for Moh's surgery when you can just flip that thing off.  But, you know, if I have that thing and I want Moh's surgery will cost 20 times more and may not be any more effective. So I was struggling with unwanted versus no more, no less.  Is that how you all operationalize that?

CO-CHAIR OKUN:  So it sounds like the distinction between over-treatment in some way or getting care that you --

MEMBER LEFF:  Right.

CO-CHAIR OKUN: Maybe that may be recommended for you, but you don't want it.

MEMBER LEFF: Yes. Or if I want over-treatment.

CO-CHAIR OKUN: Or if I want over-treatment.

MEMBER EAMES-HUFF: As Gene said, we went around and around on this one. And I think it originally started with I did not receive unnecessary care, you know? And we thought that was a little bit loaded and not necessarily getting at it because it's not necessarily about just necessary care. It could be care that is evidence-based but the patient chooses not to get it.

So we didn't want to make it something that it was just based on evidence-based, that it had some level of incorporation of the patient's preferences around the care that they're getting and what they choose to get. So it could be something that's recommended care, but they choose not to have it. So we struggled with that concept a bit and that's where we landed with it.

MEMBER NELSON: Yes, we certainly didn't resolve this one. One notion was that many people have a decision to make about what care they get and the principle of patient autonomy and freedom of good choice. And so we're in part picking up on that.

I like what you said, no more, no less. I think that's very much to the point of I'm in a position to make my best autonomous choice given everything I know and understand.

MEMBER LEFF: Yes, but so I guess the question I have is it no more, no less relative to preference, or is it no more, no less relative to preference plus some sort of reasonableness of utilization, stewardship, societal justice sort of view? I mean, you know, that's here.

MEMBER NELSON: I think we were taking this from the individual's point of view, not the societal cost-effectiveness, cost-benefit view.

MEMBER LEFF: So I would say this is one that has extraordinary potential for unintended consequences.

MEMBER BASCH: Well, I mean, I think we did not want to measure overuse and under use. We felt there are other places where those are measured and that this was really from the patient perspective and the patient probably is not in the best position to comment on what is necessary and what is not necessary since that maybe belongs more either in the provider or the shared decision making realm. But in terms of unwanted care, you know, the flip side I think is more akin to what you're saying, which I didn't not receive care that I wanted.

MEMBER LEFF: So would it be better --

MEMBER BASCH: Right? Which is not what we're asking.

MEMBER LEFF: But it sounds like then the construct that you're dealing with is not so much I receive the care I need. It's really I received the care I preferred. No more, no less.

MEMBER BASCH: You mean prefer as opposed to want?

MEMBER LEFF: As opposed to need.

MEMBER BASCH: Yes, I think that's -- Gene, you could probably comment on this, but, yes, that's right.

CO-CHAIR OKUN: And before we go, though, let's just read this, because what this is saying is I receive the care I need, no more, no less when, where and how I prefer, not the care I prefer, right, in some way. So I think there's a nuance even in the way it's written.

MEMBER LEFF: Right, but it feels to me this was constructed on the construct -- and I'm not saying right or wrong. I'm just trying to understand how you operationalize it. And it feels like it was operationalized as I receive the care I prefer in the way I prefer -- no more, no less and I got the care I prefer and the way I preferred it.

MEMBER NELSON: Right, I think that if any individual measure -- most individual measures, when they're high-stakes accountability measures especially, have the potential for misuse, unintended consequences of use. But I think what we're trying to, well, take into account, it's measures of system performance. Three part aim: outcomes, experience, costs. And that it may be in this case there would be better counterbalancing measures to get at overuse and under use. But we still would want to know if an individual feels like they're getting what they need and they aren't getting what they don't want.

CO-CHAIR OKUN: Okay. So let's go this way. And so, Dave --

MEMBER LATTS: This is Lisa. Could I just get added to the queue as well, please?

CO-CHAIR OKUN: Okay. Why don't you go ahead, Lisa, since you've been patiently on there.

MEMBER LATTS: Okay. Thank you. I just wanted to make a comment about the last comment, and I think we need to be careful that it's not about the patient getting anything they want. And I think that becomes particularly relevant as we think about some of the new trends in medicine and the concierge practices, etcetera, that it's need versus want. And I think that's a very important distinction, that we need to be sure to capture somehow that you may want something that is not in your best interest and so that is incumbent upon a physician that's person-centered or a clinician that's person-centered to explain to you why whatever he is recommending, or she is recommending is in fact the best for you even though it may not be what you want. So I just wanted to get that in there.

CO-CHAIR OKUN: Thank you, Lisa. Okay. David?

MEMBER DEBRONKART: So, Bruce, I don't know if you know, but I had a Moh's episode a couple of years ago, and so I'm on high-deductible insurance, $10,000 deductible. So I shop vigorously. I'm happy to do it. I'm a bit over the top, compared to a lot of people. But what was really clear to me that what was missing was that it was really hard for me to find out what my options were. You know, I had to dig for months to find out that there were alternatives to Moh's.

So I don't know how we implement this, but I just want to say that what I know now is that I want to know what my options are. And it can be a concise list, you know, and not just what my out-of-pocket cost is going to be, but the total cost because contrary to a lot of rumors, there are a lot of people who say, you know, I don't care if insurance is going to pay for the thing. If one thing costs one grand and one costs 20, I might be happy to take the $1,000 one. So knowing the available options.

CO-CHAIR OKUN: Right. I'm beginning to feel that there's a bit of leakage in some of the others as well, so I think actually we're spending a little more time on 1 and 2, I think. And it's a good thing to spend some time on, because these are leading into some of the other nuances that we have in the others, which is fine.

But I do want to try and finish up this concept by no later than quarter of. So we'll go around with the final comments. But I think you're hitting on some very important things that will lead us to say, oh, we talked about that when we were looking at 2. Let's see how we can operationalize it in whatever that number might be so that that makes sense.

Okay. Troy?

MEMBER FIESINGER: Yes, so I'll

make a quick point. Where I see this measure being really useful is if we look at the total picture and measures that I have as a provider. The situation I have right now is HEDIS measures mammograms. We're going to publish that. Women 50 to 75. If a woman refuses a mammogram after counseling, that still counts against me, because I didn't get it done. So if that counts against me, fine.

But if I then get positive points, because I respected patient autonomy on another measure, when I'm looked at, I can say, yes, I did worse here, but patients really thought I respect their autonomy. So I think it might play an important, counterbalanced role in looking at the big picture of a physician, a care plan -- sorry, care group, etcetera. And that's something to consider when we look at these measures.

CO-CHAIR OKUN: I think that's a great point, because when you think about -- and it's sort of the concept of that label, for example.  So if the label actually says that there's, you know, a lot of these things are being considered at the systems level, it should intuitively mean that those kinds of nuances have been considered, that on one hand the performance measure may reflect one aspect of care based on some part of what that needed to measure.  But then on another there's a countervailing balancing things that's happening that says, yes, but because we're a person and family-centered environment, patient's autonomy overrode that.  You know, so it does feel like there's going to have to be some of that kind of yin and yang.

MEMBER FRANK:  Okay.  So a couple of points that jump out at me.  Again, I would have loved to have been a fly on the wall in your room as you were having this conversation and understand how you landed here.  I'm not surprised you ended up veering into communication as directly as you did, although that was ours.

(Laughter.)

MEMBER FRANK: So we can work that out later. But it really is the case. I think Dave really hit the nail on the head there. To me this would be operationalized.

I was given opportunity to learn about care options. I had support for making the treatment decisions. I directed the choices. The care I chose reflected my goals. You know, that sort of a line of reasoning there. And this issue of need is very important, --how we define it. I don't know what I need as a patient and multiple very intelligent providers disagree about what I need as a patient.

So, you know, I think we need to come back to this concept of need after we go back through all the concepts. And it's really about is there a match between the information the patient was given, the autonomy the patient had matching with their preferred level of autonomy and decision making, and then ultimately that the patient goals were driving the process.

MEMBER BASCH: I really like that a lot, and I hope somebody was writing down those individual components that you mentioned, because I thought that really captured it.

(Laughter.)

CO-CHAIR OKUN: For purposes of -- I wrote down, get Laurie's list. So there you go.

MEMBER BASCH: There you go.

MS. PACE: And just so you know, we have a court reporter, so we will have a transcript of the -- and that's why we ask you to speak into the microphones, as well as for the people online.

MEMBER BASCH: Well, that's great. But what I really liked in particular was this idea that health concerns that the person brings with them have been addressed, because that's really what the patient knows. So I like that way of thinking of it.

CO-CHAIR OKUN: Okay. Ellen?

MEMBER MAKAR: So I just wanted to bring up a couple of points that reiterate what Dave was saying. I think when we talk about choice, sometimes that can get a little sticky. So just to think about it all the way from -- I've had friends who went for their colonoscopy, and had a choice between drinking the GoLYTELY or taking a pill. Pill wasn't covered by their plan, so they -- right? So the choice of buy that for $100, or take the GoLYTELY, you know? So which is a small example, but very common, I think.

So the whole idea of this being a measure kind of then puts in the choices that are there about payment or not. So I just think that has to somehow get into that conversation.

MEMBER MACDONALD: It's been kind of problematic for me from the beginning, because it seems like -- I believe it does need a more nuanced frame. It seems like we're trying to put two things together, the over-care, you know, or over-treatment or not. And then I receive the care I need when, where and how I prefer. And I just don't know how realistic that part is as well. I may prefer to receive my care at home, but I may not have the supports that I need to be able to do that.

I have trouble figuring out how this one actually hits real life, you know what I mean, or my experience with the healthcare system, or what the problem is that we're trying to solve with this. Are we trying to solve the problem of over-treatment, under-treatment? I'm not getting -- you know, what exactly is the problem that we're trying to solve with this one, because I think all the discussion about what it means, you know, is because it's really kind of a little blurry what it does mean.

MS. PACE: I think that's a good

question, and I think this discussion is very helpful. And as we talking about yesterday, this will be kind of an iterative process. Maybe we'll come back and say this is really not a core concept, you know, because certainly overuse and under-use relates to effectiveness of care and what the evidence says, you know, treatment should be. So we'll definitely revisit it, because I think, you know, you're all raising some important issues.

MEMBER DEBRONKART: I'll bust in one last time. This is where once again I come down to we may not know how to micro-measure the details, but we can certainly ask, do you feel like you got what you needed?

CO-CHAIR OKUN: I think the other thing that's clear to me, too, and I think you raise a great point, Mary, is that this actually dovetails with the, you know, core where we're looking at collaborate in decisions. So where you learn about my preferences for location of care, for example, is when we collaborate in a decision that's going to need to be determined.  Can I get it at a home or can I not get it at home?  And if I can get it at home, but it's going to cost me more because I need someone there with me to do it, well, then I balance out that decision.

So it feels to me like we're starting to reveal and illuminate some opportunities here where we say, well, this may be something that comes under something else, right?  And that may be more appropriate not as a core concept, but something that's sort of a sub-concept.

MEMBER MAKAR:  Sally, can I just jump in with one more thing?  It may be appropriate for some conditions and not others, when we look at that, because for some intractable conditions, or what comes to mind is hard-to-diagnose or chronic pain.  Those can be really tough ones to know that you're getting what you need and what you want.

CO-CHAIR OKUN: I think that's a great point. And Annie brought that up earlier in terms of, who is the denominator on some of these things. And I think the other piece is when we start thinking about things like promise measures where we're asking certain things that are actually more general and generic measures of how a person's feeling.

And then we think about things that are more PRO condition-specific. So those may help to illuminate where this particular condition is going to override that person's ability to be able to set the tone of where they want to be, because this is always done in a certain place or whatever. So a great point.

MEMBER DEBRONKART: I just got a flash. For some reason it just dawned on me that nothing I think that we're talking about doing here -- all of this will apply to people who are actually in the system getting treatment, right? So none of this will touch -- like one thing that hit me, in the other countries I visited people have just been stunned that pregnant women don't automatically get all the care they need, you know, and that newborn care isn't just automatically covered and everything and, I mean, with all the consequences of that.

And so I wonder what do we do to capture like did you get what you need among the population that never even gets in the door? And it occurred to me one thing we might want to suggest is that we set up -- do some sort of field polling in shopping malls, supermarkets, whatever and ask people -- I mean, give them a free cup of coffee if they'll respond to this survey asking are you able to get what you need?

CO-CHAIR OKUN: That's a great thought. Okay. We're going to move down. And we have about another four minutes or so to finish up this one and we're going to move onto the next ones.

MEMBER LEFF: So when you were talking through the concept I was wondering whether -- something that our group is interested in. Did the notion of treatment burden come into play as you were talking this through? If so, how? Did you feel it was captured? Because that's something that jumped out at me.

MEMBER CONNOR: No, I was also challenged by this particular core concept, and in thinking that patients' perceptions of what they need will be hard to quantify in a measurable way. So I do like "I did not receive unwanted care," but when you think about does this relate to the core concept, it really doesn't, since that's need versus want. And I would caution the group to adhere to the actual core concept, as we're thinking about how to measure them.

MEMBER EAMES-HUFF: I think when

we were talking about this one -- and it was earlier in the group discussion Gene had used the analogy of, I'm the captain of my ship to sort of talk about that. And I think that resonated a little bit with me in terms of thinking about this. It's a little bit different than the words, but really having the person at the center. And I'll just say I was struck by -- I came in with the discussion around mufflers, so I don't know if I missed the beginning part of it. But that, the analogies or doing something like that really helps bring these to mind a little bit more. So when we're thinking about how to describe these things, if there are other ways that we can use analogies or other ways of looking out to sort of make it easier to understand.

CO-CHAIR OKUN: We also had a suggestion of trying to integrate some vignettes into this, to sort of say here's how this would come to life. So I think that's a really good suggestion.

MEMBER WALLING: I just actually wanted to agree with what you were saying earlier about the care I need and the care I want. Often in order to figure out what those are requires a quality conversation that's ongoing and changing over time. And so, you may not know that there was another option, and so a lot of times people don't know that they received unwanted care because they didn't have the opportunity to -- so I think getting at that, like you said, in other areas.

MEMBER NELSON: I mentioned yesterday the IOM Chasm Committee work, and living with the paradox of I get exactly what I want and need exactly when I want and need it. And, you know, in a sense we're living with that paradox and discussing it today. And if we think about looking again at the Chasm report's principles and then recognizing that sometimes it's not black and white, what

I think I want may not be what I need. And sometimes science doesn't even know the best answer, oftentimes doesn't.

So we're in an area where it's not always clear and yet in general, I think, we're trying to put the individual in a position to make the best choices, given what's known from the evidence and care for people like you, as well as what they think about their choices and how those choices impact their life, their health outcomes, their well-being.

So there's a bit of this paradox here of want and need, and that's real. And science is not always the answer, because for this particular person with these set of conditions we really don't know. We're out of science.

CO-CHAIR OKUN: Okay. So I'm going to move us onto the next one, but before we do, I've made a couple of notes on this thing that we have assigned the different groups. And I picked up from the two concepts we've already talked about some commonalities and things that have to do with preferences, communication, convenience, information. Under that options and choice. So there's a lot of things I think that are imbedded in these two concepts that actually are going to influence some of the others as well.

On the first core concept, does that feel like a label? I mean, I know we have to define, you know, what it means for holistic care, but does that feel like a label item, like this particular system really attends to the whole person?

(No audible response.)

CO-CHAIR OKUN: Okay. The second one, are we in agreement that that may be somewhere else within another core concept, that it actually -- okay. Does that feel like a reasonable assessment?

(No audible response.)

CO-CHAIR OKUN: Okay. All right.

MEMBER FIESINGER:  I agree Number 1 is a label.  It also is a marketing slogan. And I love my system, and my system will slap that on a billboard in five minutes, because that's what they do with all their quality measures.  So I don't it want to just be a marketing slogan, because then everyone's a medical home and everyone treats the whole person.

CO-CHAIR OKUN:  Yes.

MEMBER FIESINGER:  So there needs to be some meat and teeth.

CO-CHAIR OKUN:  Show us what you do, right?  Okay.

All right.  So let's move on. Michael, do you want to lead into the next group?

MS. PACE:  I was just going to say I'm going to tape up these two back there and then after we, you know, go through the core concepts for the next group, we'll tape them up and we'll have a chance to look at them during the break.

MEMBER LEPORE: We do not have a handout.

(Laughter.)

CO-CHAIR OKUN: Your work sheets that you're going to work from, right?

MEMBER LEPORE: So we worked through concepts 3 and 4. This was Annie, Mary, Sally, myself and Chris, but Chris is not here with us today. We each have the measure concepts that we documented from our work, pulling them together, and we'll each present those distinctly.

One thing I do want to emphasize is in the chart, which I think is useful to have out, that NQF provided there, are already sort of examples here. And we stayed away from those, which may or may not have been preferred, but they're already here and documented. I think they're strong measure concepts, but because they were already here in the document, we did not address them. And we looked to fill in additional sales that were not yet touched.  And in 3 and 4 this did include structure and process measures, rather than any outcome measures which were already filled in.

So just to begin with the No. 3 core concept, my care partners treat me and my family with respect, dignity and compassion. I'll just start with one of the measure concepts we developed was the idea of a culture of respect.  And in particular a sort of catch phrase maybe, I thought it was, some caring for the caregiver, actually.  And this is a system that treats their clinicians with respect and dignity knowing that when clinicians aren't treated as such, they very well may not treat their patients in the same way.

And what we were thinking about, you know, what sort of patients is this relevant to?  All.  You know, we thought this was pretty much relevant to all patients and the data source would actually be considered a clinician survey, and that this would be an assessment of leadership.  So really this idea came from a lot of discussion about leadership.  It's like, okay, well, it's sort a leadership system.  It's a systems, or systems leadership is who was being measured in this culture of respect idea.

And the other one I will briefly describe, and then we'll go on to are other team members is again with regard to my care partners treat me and my family with respect, dignity and compassion.  There was a lot of talk and during some of the vignettes yesterday there was discussion about privacy, and the issues of privacy and the environmental design of care experience and how this influences patients' experience of privacy and of feeling that they've been treated with respect.

So we described it, sort of, as respectful environmental design that supports privacy for patients and their families, as well as being welcoming for family. And this also drew back to this idea of the percentage of space given to waiting rooms, for instance. And again, relevant for, you know, all patients across settings. Thinking that this would potentially be a patient survey, there certainly could be an environmental assessment and this is sort of an assessment of the facility itself, wherever the care is taking place.

So we could move through. I think we have two more in concept 3.

MEMBER MACDONALD: Sure. So we were looking at what the components are of being treated with respect, dignity and compassion. It seemed like an important one was the amount and quality of time that's being spent with me. I think we talked about that yesterday, if you feel that the clinician is rushed or doesn't really have time to speak to you, that is -- And as you were saying earlier, Sally, you know, we're talking about the whole person. It's my job to tell you what I needed, but with some clinicians you have a sense that, you know, your 10 minutes is up, and you don't really have time to listen to me tell you about the whole person.

So we really wanted to focus on trying to find a way to maximize the amount and quality of time spent, but I'm not sure that we came up with a measure that's really operational. We said that -- we were big on structure and system measures, but that whatever the facility is or the institution should have a protocol that allows for flexibility in terms of time.

There should be a structural measure, some, you know, protocol in the facility level that allows for enough staff for there to be sufficient time to be spent with each patient, and then some flexibility along those lines. So that's kind of as far as we got, in terms of coming up with a measure.

CO-CHAIR OKUN: Yes, I'm actually channeling Chris. He's not here. So the process measure was person-centered communication. And I think this sort of overlaps and leaks back and also leaks forward, because we have one on that. But I think, you know, in our conversation yesterday, it's just so critically important to the respectful experience, feeling, you know, that I have a sense of dignity as to who I am, and ultimately compassion. Compassionate care, oftentimes people equate that with end-of-life care. I think what we're trying to say here is that compassion needs to transcend at all levels of care. And that requires communication.

So high levels of elicitation, checking for understanding, open-ended questions and allowing people to be able to respond in ways that you -- again, this goes back up to time. You know, you allow me enough time to be able to tell you things that I need to share. Positive support, so we have empathy that communicated. And legitimizing who I am and what I'm saying and recognizing that it has value. Bidirectional information giving, so that there's an opportunity for that kind of stuff to go back and forth.

We felt that this was really an all measure, but that actually the data sources could vary. We could have a patient exit survey similar to what, you know, Dave has suggested all along, which, you know, how did it go? Did you have the privacy you needed in order to be able to do what you needed to do, in terms of that? Did you have the communication you needed?

Chris actually used this in a couple of other examples and it's something that hasn't come up, but audiotaping and videotaping. Having the opportunity again maybe for some vignetting, you know, to be able to take the opportunity to the immediately to hear what feelings and what the experience was actually like.

And then a clinician survey. And I think this goes back up to the one Michael presented, that we respect and we consider clinicians respectfully and we honor their dignity. And we believe we have to treat them with compassion as a systems approach, that if done well hopefully will spill over to the patient experience in a positive way.

So the performance measure is measuring clinicians. It's measuring the care team. It's measuring the system and the leadership in the system to establish this type of culture in terms of the communication that can get supported at the patient-centered level.

But I also will come back to that it also -- it means that the patient needs to tell us their level of interest in this bidirectional giving and communication, because some, as Bruce said, may not want any.

We need to be understanding of what that looks like.

MEMBER NELSON:  Could you say what you meant about the videotaping and audiotaping?

CO-CHAIR OKUN:  Yes, again, I'm channeling Chris, but I think his perception on that had been, you know, one of the ways that we can really get at what people feel and think is to actually hear their voices say it, and then to be able to use some of that in a way that you could replicate that with other people, to actually show what the experience was like.

So just getting it in an audio version, versus just on a survey-type thing, that it has power, it has translation that people can actually appreciate.  And sometimes maybe in the communication piece it's also done in languages that are not English, you know, so that you actually have the ability to translate some of that stuff about what is person-centered communication and how does it feel.

Does that treat you with respect? Did you feel that you were honored in terms of your cultural preferences and stuff like that. So it spills over into a lot of places, but I think respect, dignity and compassion has such a culture to it that we have to figure out some ways I think of honoring that at a high level.

MEMBER CONNOR: Okay. I would just add, in terms of metrics, something to the effect: my caregivers made eye contact with me when discussing my plan of care. And this is, I believe, particularly important.

I can quickly tell you a case. My sister who was hospitalized for pain control had the physician from the pain team come into her room and while he assessed her pain he was flipping through the newspaper, looking at that rather than looking at her.

MEMBER LEPORE: And I certainly

appreciate the example and it brings to life the importance, but I also know culturally that might not be comfortable for some folks to have eye contact.  So it could even be around the lines of I felt listened to or I knew the provider was listening to me, because eye contact may not be comfortable for some groups.

MEMBER CONNOR:  Just one other quick example.  The health editor of the Wall Street Journal -- and this has been openly discussed in the paper, so it's not a HIPAA violation, had her treatment at the Dana-Farber Cancer Institute, and was furious because the folks at the registration desk did not make eye contact with her.  So I appreciate, though, the cultural differences, but it's a real need for many patients.

MEMBER LEPORE:  Yes, and I think this example is particularly important, because it's tying in even the folks at the registration desk, not just the physician.

And I think it's why I really like this culture of respect idea as well, because it is everyone who touches the patient. And it's on the phone when they call, it is at the desk when they arrive, it's the security guard. Everyone's affecting the patient's experience.

CO-CHAIR OKUN: So, you know, I'm mindful of the fact since I was in this group, and going back to the Group 1 where they had on their first core something about training, one of the things we didn't attend to here; and I think we brought it up in some other conversation, but what strikes me from Maureen's comment there, you know, eye contact in an intimate contact when you're actually communicating about something that's intimately about your health or something, seems different to me than the eye contact at the administration desk when you're checking in.

There may be a cultural issue that, you know, you don't make eye contact with someone, but you learn that through some other way, maybe that you understand that person's preferences. So sometimes that's a violation of someone's person, place or whatever, to look them directly in the eye, but that's not something you know until you sort of understand the cultural issues, right?

So great points, but I do think what this is raising is that the culture for this particular core concept of the institution or the system is just going to be so critically important.

MEMBER LEFF: Yes, I think I like the focus on communication, and I think a lot of the constructs that you all talked about are captures in CAHPS. I think a lot of those exist. So I would definitely take a look at those.

The other thing, and this is more of a global comment and just my impression as we're talking through a bunch of these concepts, yesterday a lot of the discussion which made my heart sing was this notion that we want to think about this beyond the center, beyond the academic center, beyond the hospital.  A lot of the kinds of things we're talking about now kind of feel very -- we're going to do this in a way that will be very -- not even easy, but perhaps doable for those kinds of centers.  But remember, most care is not happening there.

We really need to think about how this gets implemented beyond the academic center.  I think we should really not be thinking about the -- I think that we should push ourselves to think way beyond that, because if we don't, we're going to get stuck in an approach that really won't have any meaning.  And I can tell you that most academic centers will go the way of Troy's practice and whip it through, and quite honestly create work-arounds and work processes that actually will have significant unintended consequences.

CO-CHAIR OKUN: Can you make a suggestion of how you would translate this into an environment outside of a system, for example? That would probably be helpful.

MEMBER LEFF: Well, I think you can, but I think, don't think that this will be easy or, you know, we need one more question about eye contact to make sure that we have person-centered care. I think the paradigm in our head should be, you know, the non-affiliated clinic, the house call patient. You know, think beyond, because those people need patient-centered care as well. And that's where most care happens.

CO-CHAIR OKUN: I'm going to push back just ever so slightly, and somewhere along the way that interaction is starting somewhere. So, I mean, I did community care most of my career, but yet it was initiated from some -- so there's some way that I get into that home as a provider of sorts, right? So somewhere in there, there's got to be a system of some sort that's actually directing that. Or, I mean, I was also an independent practitioner, so I was directing myself when someone would call me and ask me to come visit them. So I needed to internalize some of these myself, but I didn't have someone, sort of, holding me accountable to that.

MEMBER LEFF: Right, and I think accountability is fine. I think it does have to start somewhere. But I think it feels like there's an underlying assumption that there will be Big Mama system to implement all of this, and it will be easy.

CO-CHAIR OKUN: Got it.

MEMBER LEFF: There are big costs, you know, to allow these things. And so just to keep it in mind.

CO-CHAIR OKUN: And some of it I think also may overlap into some of the others, where you have coordination of care and transition of care where some of that should -- you know, you should have to have that kind of thing transcending from one place to another. But that's a big megillah thing. All right. So we're going to start down that end, is it? Lori?

MEMBER FRANK: So I'm just wondering about the potential for putting all principles of person-centered care into a single core concept. You know, so I agree with respect, dignity and compassion. Maybe we should also put honesty and transparency in here? And then that translates really well, I think, into the food label because you can say, principles of person-centered care are evident and are followed in this setting.

CO-CHAIR OKUN: You're suggesting Concept No. 8 and Concept No. 3 get married in some way, or brought together?

MEMBER FRANK: So, and I should know --

CO-CHAIR OKUN: Because you mentioned honesty, transparency and --

MEMBER FRANK: Well, there's a lot

of other principles that might come out during the discussion.

CO-CHAIR OKUN: Okay.

MEMBER FRANK: But, yes, I'd say let's say it's about the principles of person-centered care are reflected in this environment. And then everything can go into one.

MS. PACE: But how would that be useful other than someone just saying that? I mean, I'm trying to get at what you're -- because when we were thinking of the label idea, it would be very specific things that you could kind of know, like what their mode of communication -- you know, and certainly on the label you could have their statement of person-centeredness.

MEMBER FRANK: Yes.

MS. PACE: But beyond that, how would you know it's more than just words?

MEMBER FRANK: Right. So it's patient perception, but it's much like a patient's perception of whether the whole patient is taken into account in the setting as well. So I view it as quite similar. It's global. It's arguably not specific enough for this sort of a measure, but I think it's worth considering that the patient perception of the extent to which these principles even exist and then are adhered to is worthwhile.

MS. PACE: Okay. So you're thinking that there would actually be a measure, like percentage of patients who -- you know, whatever the specific question is, and that would be something that would go on the label?

MEMBER FRANK: Right.

MS. PACE: Okay.

MEMBER FRANK: And, I mean, I think part of this discussion is about making those principles --

MS. PACE: Right.

MEMBER FRANK: -- more evident.

MS. PACE: Right.

MEMBER FRANK: And to the extent that some culture has to change in some settings, then this would drive that.

MEMBER FIESINGER: Okay. So one thought now becomes two. So to Bruce's point, I think, like individual and small group physicians, and even though we're in a big system, we're 10 miles from the mother ship hospital in a community, the issue to make it useable is that it be simple and not cost very much, because if I went to the family docs in Texas and said you need to do this, they're going to say why? What's in it for me? How much will it cost? So it's got to be cheap. It's got to be simple. And if it can be a piece of paper they hand to a patient and they put it in a file, that's workable.

As far as the privacy, I like this concept a lot because again as we're pushing quality measures, if I ask women for a copy of their Pap smears, I get answers ranging from: you mean, you don't already have it? To why do I have to sign a release to get it from my doctor?  To why do you want it?  So a whole spectrum of views of privacy.

And I won't get on a soap box about HIPAA, but HIPAA's had huge unintended consequences, from the woman who doesn't want me to know what her Pap smear was, so I get dinged, to the patient who wants to know why I don't already know it.  And this would be a way for a patient to articulate to us a little better what their view of their privacy is. Since HIPAA defines it too specifically, this lets it be a little bit more mutable in a more global concept.  Again, put it on my sticker, so when I get dinged for something else, I can say, see?

CO-CHAIR OKUN:  So the other part of privacy here though also was structural, you know, the actual environment of care in terms of being able to promote privacy and stuff.  So I just wanted --

MEMBER DUBOW:  Actually, I really

think that environmental piece is really important, and it is structural. But I didn't give a vignette yesterday, so I'll give a quickie.

I had oral surgery a year ago, and I had an email exchange with a member of the HIT Policy Committee. And she sends me a note and she says, I see you have an appointment with Dr. X tomorrow. And I thought, how on earth does she know that? So I asked her. And she said, because I'm sitting in his office and I can see your name on the board. Small practice. This is no system. This is a small practice. And he did a great job. And, you know, it was dental surgery. I didn't really care, but you know, that's a big deal. And it's just a big deal.

So I think the environmental factors -- in addition accommodations for people with disabilities, people who are obese. You know, there's a whole range of environmental things that really do reflect the need to accommodate, to deal with people who are getting here.  And which is inherently person-centered.

So I think the issues around privacy.  The queuing.  You know, if you are in a system, you -- it's like when you go to an ATM machine.  You don't stand over somebody's shoulder.  These are things that don't necessarily dictate a system in order to be able to do it.  These are thoughtful, predetermined practices that are designed to take into account people's needs-desires for privacy.  So I think that's a really good one.

I just want to come back to the NQF measure endorsement process again, because I'm thinking about the -- we endorse measures for quality improvement and accountability. And Gene tells me there's a good article on videotaping people, but I don't see that as an accountability measure.  I don't see how we could operationalize that and publicly report it in any way that would be easy.  I just don't see it as practical.

I think it's a terrific teaching tool. I think it's a QI opportunity, no question about it. I think that there would be lots of patients who would have some reluctance to do it, particularly older people. But I just think we have to think about measures that are useful for the dual purposes of NQF endorsement, which is quality improvement and accountability. So, I mean, I just think we have to keep that in mind.

I just want to make an observation about the label stuff, because it's a really nifty idea. I actually suggested yesterday that they put the number of calories on those little peppermint balls because --

(Laughter.)

MEMBER DUBOW: -- they are addictive. And if we knew, it would allow us to be a little bit -- and now that I know how many calories, I won't have quite so many.

But, you know, so what you put on

a label feels to me very challenging actually, because I think it should have the rigor, the information should have the rigor of certainty.  It's not quite a best practice. I mean, NQF publishes best practices, and it's not quite a best practice.  If you put that thing on there, you need to know for sure that that's it.  You know, you can rely on it.  And it can't be something where the evidence is uncertain, unknown.  So I think it's a great -- I mean, we know the nutrition label, at least for some of us, is very effective, but I think we need to be very careful about the kinds of things we think about putting in that kind of a list because we don't want to lead anybody astray.

CO-CHAIR OKUN:  Okay.  So do a time check here.  So we'd like to finish up this one in the next five or so minutes.  So we'll go to e-Patient, Dave.  And then, Kevin, you have your card up.

MEMBER DEBRONKART:  Not sure how

this will affect things, but I think we need to be very alert to what's going on with retail clinics, because it's funny, there's been one in my mother's neighborhood for three years, and it's only within the last few months apparently that use has picked up.

And the punch line here -- so the were you able to get what you wanted, you know, in a way that worked for you? Last fall I spoke at an event where Atul Gawande gave the lunch keynote, the famous surgeon, and he said something fascinating. He said when minute clinics came out he sort of thought, eh, who needs this, but that fall when flu shot time came, even though he could get a flu shot for free in his building, it was inconvenient. It was difficult for him to get there. So he ended up getting it at the new minute clinic in his own neighborhood.

So I hope whatever we do, it will apply just as well. Because, also, in terms of data, I'll bet we'll start to see it, because they depend on convenience essentially, you know, being a good place to do business with for their business.  I bet we'll they are at five stars constantly.

CO-CHAIR OKUN:  Well, they also are within an environment where customer service is something of consideration.  So it's something to keep an --

MEMBER LEFF:  Yes, CVS and Walgreens are going to become the new primary care sites.  Make no mistake about that.  Make no mistake about that.

CO-CHAIR OKUN:  Walgreens' mission is to be that, yes.

MEMBER LEFF:  Yes, Walgreens will --

CO-CHAIR OKUN:  Your neighborhood clinic is right here.

MEMBER LEFF:  They will do that. So, you know, so I'm thinking about denominators.

MEMBER LARSEN:  As I reflect on

this, I put these into three buckets, and I am happy if someone would tell me that they don't agree with this, but I heard first respectful organizational culture, respectful environment and respectful communication.

There's kind of three distinct things. And the reason I liked those is that they work well together. So respectful communication tends to be individual to a patient, and that works best within the context of respectful organizational culture and the respectful environment. Heroic individuals trying to do this that aren't supported by their organization, both physically and operationally are thwarted time and time and time again.

But you also can have a terrific environment, and even a terrific leader and a horrible mean person sitting in the doctor's office. So they work together as a package. And I really like the environment. It's one that I've long kind of felt passionate around.

So just was a sort of reflection.

MEMBER WALLING: I was just going to say with the communication, that it's sort of broad, respectful communication, and which is also being open to patients' needs sort of like on a longitudinal basis as well. It's not just the communication on a one-on-one one-time setting.

MEMBER EAMES-HUFF: I'm struck by some of the conversations that we're having that resonate with something that was done about 20 years ago. And this was the Picker Institute's Principles for Patient-Centered Care. And many of these overlap with those particular principles, like the respect for patient preferences, the care and compassion. So I think it would be helpful to go back and look at that.

Those principles were based on consumer patient feedback, lots of focus groups, but also with clinicians and others involved in healthcare. It was really wide.

And they still have on a website, I think it's for the Institute for Patient and Family-Centered Care now, vignettes and little videos of what these things mean, of patients talking about it.

So I'm not saying we have to do it exactly like that, but I think there are things that we can learn from that and think about how to modernize it, because I do believe, and I hear this from other folks, of, you know, the Picker surveys were developed about 20, 15 years ago, and we're operating in a different environment. So we didn't have high deductibles then like we quite do.

So some of these concepts may be the same, but how they get operationalized may be a little bit different, or what they really mean may be different based on -- but some of them I think are tried and true. Just feeling communicated is sort of timeless.

CO-CHAIR OKUN: I think you raise a really important point and I trust that NQF in, sort of, their landscape of what's out there, too, is starting to take -- has done some of that inventory, but I do think there's so much to learn from -- not only work that was done 20 years ago, but yet even things that are being done now that sort of overlap with what we're doing here. So there's just a lot of resource information, a lot of really smart people thinking about these things. So the principles and the core values of it all I think are really going to be -- we'll find some overlap for sure.

MEMBER MAKAR: So in reflecting on that conversation today, I was struck by the fact that communication keeps emerging as something that is, and it's not surprising, is central to patient-centered care. And I agreed with Lori's comment about whether or not these particular core competencies are necessarily -- whether or not there may be some benefit to sort of looking more broadly at these, at a single domain rather than multiple concepts just so -- thinking about communication, for example, a number of our core concepts touch on dimensions of communication.

There's a very large literature around effective communication between patients and their providers, that touch on, sort of, critical elements of interpersonal rapport that reflects trust, respect, the ability -- feeling comfortable disclosing personal information to a physician, information exchange that the patient is able to disclose the information that's important to them about their concerns and that the physician listens and provides back information about their prognosis and their treatment options.  And that there's then this collaborative decision making process where the risks and benefits are described to the patient in a way that is consistent with what -- the information that they want to hear.

And it seems like that literature

is very far along, and well-established and there are -- you know, that's been studied extensively using audiotapes, encounter data, qualitative methods and that we have pretty good measures of CAHPS at the individual level that touch into those domains.

One of the things I'm struggling with in this activity is the fact that we're talking about person-centered care sort of seamlessly across the continuum. And some of the vignettes yesterday -- Uma's vignette touched on the person-centered experience not just within the health system, but really the ability of the health system to coordinate with housing and with the school system. And in the discussion today we really haven't touched -- we've had much more of a health system approach, thinking about a physician office.

And I guess I'm wondering whether that is part of our charge, to think about, more broadly, how do we think about person-centered care when it's, you know, moving beyond what we know a fair amount about to thinking about, you know, the person experience more broadly for people who are disabled and who are having to navigate the social service agencies and housing.  And is that part of our charge?  And if so, you know, should we be trying to bring that into the discussion more?

MS. PACE:  And I'll just say, yes, we want to think across -- that's not restricted to settings, but it's an interesting observation, because I don't think the discussion has said this occurs in the doctor office.  You identified that it was about the doctor office.  Bruce was identifying that it was about the academic health centers, but I think, you know, a culture of respect can happen in any setting or across settings.  But you're absolutely right that we need to be thinking more broadly.

MEMBER EAMES-HUFF: So I appreciate that pushback, and I think that you're right, I perhaps have made an erroneous assumption. But I do think we know much less about -- we have fewer measures that exist now and we know much less about what high-quality coordination looks like across -- about best practices in that more broadly.

CO-CHAIR OKUN: I think actually you hit the nail on the head, which actually is really part of the charge, is uncovering and illuminating where gaps and measurement are. So I think it's going to be pretty clear once we -- and I think what we're starting to do is starting to see that there are some common themes to person and family-centered care that are bubbling around communication, around culture, around convenience, around information giving and sharing and things like that.

And then I think the challenge will then be, well, we may have some measures for this in some of the more, you know, established institutional settings, but you know what, we don't have any measures for this in the retail clinics, or we don't have good measures for this in home-based environments. So I actually think that's exactly what we're trying to get at.

But I wonder, Karen, can you clarify for us, do we need to be that explicit, or can we be more broad-focused to say here's the themes, and maybe Kevin can articulate, that we feel have to be a part of person and family-centered care understanding that we're illuminating for you some opportunities to identify where those gaps are.

MEMBER LARSEN:  Yes, so I think it's the latter.  This is what's called a gaps activity, and the idea is to really elucidate where the gaps are, and help prioritize where the investment should be in those gaps.  It's not to say that in the course of this work we're going to get to all the measures that we'll ever need, and we have all the sophistication. That is for the next set of investment. But this is to help guide us to say where should that next set of investment be? Where are the high-value opportunities? What are things that make sense and how are we sure that we're not trapped in our old paradigms? How are we really thinking new and different, as we make those future investments?

CO-CHAIR OKUN: You know I just want to remind us, too, one of the things that I'm struck by is, you know, so much investment has been made in sort of the EHR integration into institutional systems and for a lot of physician provider offices, but you know, there's very little in the long-term care setting. There's very little in the home care setting. There's beginnings of, you know, sort of the vendors starting to think about those environments. So some of what we may identify is that some of these settings are not quite even ready for measures to be implemented, but we may need other structures in place before we can really fully help them integrate different types of measures.

But you're shaking your head, so I'm going to --

MEMBER LARSEN: So I've been lucky enough to be coached by a lot of Lean experts, and one of the principles of Lean is measure, but don't over-invest in measurement. And it turns out that some of the most terrific improvement activities have been by somebody with a piece of paper and a clipboard making little hash marks to note what is going on. And there are just fantastic innovative projects across the country that have done all of their work in that way.

So an example of this is ThedaCare, which many of you might know, use their medical assistance to measure the waiting times in waiting rooms of all the patients in their clinics. And all they did is they had the medical assistant actually write on the papers schedules the waiting times. And ThedaCare, over the course of a year was able to virtually eliminate the amount of time that the patients were waiting for their providers. And they didn't have any infrastructure investment other than the staff they already had taking a little bit of extra time to mark something that was important and track and trend it.

CO-CHAIR OKUN: Having been someone who's been in that sort of, kind of, situation, where you're out there doing this on your own by the seat of your pants, the one thing that you end up with is sort of a really great project that doesn't get up-scaled. So I think we need to be careful that, yes, there are things that are being done that are really innovative and really great and some people are really smart and doing some wonderful things wherever they happen to be, but you need to invest in our ability to be able to bring those forth.

So if we identify that there are, sort of, core things that we think have to be at the systems community and, you know, even at the most local level, then we need help to be able to bring them forward.  And the one mechanism that has brought some of this forward unfortunately for, you know, good or bad, has been, you know, data collection systems, right?  So they're not necessarily the solution, but they are one area where we actually have gotten some traction.

So, all right.  We're getting really tight on time.  So let's see.  Any last comments and then we're going to move on to the next one.  Mike?

MEMBER LEPORE:  Yes.  Well, we've experienced a bit of drift from the concept here, but I think where we've gone to is extremely important.  And only in Concept 8 do we really have this discussion of coordination across settings, but even there I think we're all thinking of that. And as a lot of the examples show, we're thinking of that in terms of coordination across care settings. But I think we have, if we want to challenge the paradigms that we're working in, we may want to consider coordination across departments, Department of Health and Human Services, Department of Transportation, Housing, things that are affecting people on a very grand scale, these sort of inter-sectoral management gaps of measurement.

CO-CHAIR OKUN: Well, just remind us that actually our definition didn't put in care.

MEMBER LEPORE: Right.

CO-CHAIR OKUN: So it's says across settings and time.

MEMBER LEPORE: Yes.

CO-CHAIR OKUN: So I think we opened up the opportunity for, you know, really a broad view of that.

MS. PRINS: I just wanted to make a quick reference back to our Care Coordination Group, which met last week. And their charge is actually looking at care coordination, sort of, between primary care and community health, so they're grappling with a lot of these issues. And I've been making some notes to take back to them, and I think that's going to be some internal discussion that we need to have a staff.

But one of the things, as you all were talking about the whole person and taking that into account -- one of their, sort of, fundamental things was we need this comprehensive assessment that gets at what are their social needs, what are their behavioral health needs, you know, what are the families' needs, all of those things. So I think these are starting to piece together nicely, and it will be up to us to make sure that we make those connections.

And the other thing I would say

is: on Tuesday and Wednesday next week is our Health Work Force Group. And so some of the things that came up around training, I think those will be at the forefront of some of the things that they talk about.

CO-CHAIR OKUN: Okay. So in the interest of time we do need to get to Number 4. Gene, did you want to make a comment, and Laurie? And then we'll be finished with this one.

MEMBER NELSON: Yes, I'll be brief. Yesterday, Sally, you mentioned sometimes we take a provider-centric view of person-centered care, and what I've been thinking about is: we might end up with sort of a short-term, long-term approach to filling the measurement gaps that will come forward. And that if we looked at the promise work now ten years into it, they start out with a very comprehensive framework, the WHO framework, and then over time they've developed great measures. And it may be that we need to, in the longer term, sort of, rethink the person-centered care frame and start to build out short-term and long-term measures that are appropriate to the frame, and that capture not only let's say the healthcare experience across the continuum, but also social and community factors as well. So that was the thought.

CO-CHAIR OKUN: And I think that there's networks and communities that are emerging that are just novel and we haven't really seen them before. So, you know, there's going to be opportunities I think for that as well. So I think the idea we are charged with sort of thinking about these from a short and long-term perspective.

MEMBER RADWIN: I just had a very specific comment following Jennifer's example of the principles of communication that have been well-researched. And what it brought to mind is people, clinicians and others in different settings have the gift of time with patients to do that great communicating. So the principles that you derived about physicians have also been derived about, you know, my discipline in nursing, but also TO and PT. And when you have the time to be with a patient to listen respectfully, to hear about them as an individual, to build that trusting space so people can be authentic, authentically represent themselves, to build trust, I think we need to zoom out a little bit about where the communication lives, and who has the opportunity to communicate.

Honestly, in some of my work people describe the housekeeper as delivering the best patient-centered care, because they were in the room, you know, and talking to them, probably in a language they understood. And so I think when we think about patient-centeredness we have to look at all the opportunities that we have to provide patient-centered care. And one of the things is the time to be attentive and, you know, where you sit in the organization interfacing with a patient can matter in that regard.

CO-CHAIR OKUN:  I'm reminded of about a 30-year-old cartoon I used to use in some presentations, and it was a depiction of a patient in a bed, the housekeeper in the room doing their thing, the physician and the nurses and others outside the door and the caption reading, if you want to know you're dying, ask the housekeeper.

(Laughter.)

CO-CHAIR OKUN:  All right.  So let's -- oh, go ahead.

MS. PACE:  Yes, I think we probably need a break, but why don't we real quickly just see if there's anyone on the line that wants to make a public comment and then we'll take a break and then resume.  Operator, is there anyone on the line, the public line?

OPERATOR:  If you would like to make a public comment, please press star, then the number one.

(No audible response.)

OPERATOR: At this time there are no public comments.

CO-CHAIR OKUN: Maureen? Maureen, why don't you come up here, because I'm not sure how the -- we always have trouble with the microphones, so let's --

MS. DAILEY: Hi, I'm Maureen Dailey, senior policy fellow with the American Nurses Association. I'd also like to support the comments that Laurie Radwin made about the importance of the time to authentically be with patients and for patient-centered care.

In my own experience recently with my daughter who was misdiagnosed in two academic medical centers, when we got the answers and got a path to patient-centered care, and very important decisions about what she had to do -- and the body part that was important to her that she had to lose, was that the surgeon spent one half-hour going through everything with us. And she had a busy office, but took the time to be with us, and to understand what her goals and outcomes -- and to hear what she had been through, from a productive member of the community with an important job to being non-functional and not heard in the two other academic medical centers.  Thank you.

CO-CHAIR OKUN:  Okay.  I'm a real worker, so I wouldn't have given you a break, but we're going to take a break.

(Laughter.)

CO-CHAIR OKUN:  And let's be back here in 10 minutes.  So 10:40.  Thank you.

(Whereupon, the above-entitled matter went off the record at 10:30 a.m. and resumed at 10:43 a.m.)

MS. PACE:  Okay, everybody.  Let's reconvene.

Okay.  You are being looked at now because you're still standing and we've asked you to return to your seats.  Peer pressure is needed.  Look, they just keep talking.

CO-CHAIR OKUN: Okay. Well, we're sensitive to time, you know, and we want to be sure that we get to attend to everything. So the plan at this point, just so that we're all on the same page with it, we're going to do Concept No. 4 now. We're going to try and get through that in about 15 minutes or so.

We're going to move to the Group 4 7 and 8 concepts because Bruce needs to take a phone call at 11:00. And then we'll come back to the Concepts 5 and 6 when he gets back. Sound good?

(No audible response.)

CO-CHAIR OKUN: Okay. So, Michael, you want to lead us into Concept No. 4?

MEMBER LEPORE: Great. Yes, so Concept No. 4 is; we talked about this a bit yesterday, I collaborate in decisions about my care to the extent I desire or am able, or I choose the care partner I prefer to collaborate in those decisions for me. And again, because we had process and outcome measures identified in our existing table, we really did focus again on structure measures.

And the first one that I'll share is what we called an information commons. And this was one of Chris' terms. It was really an information sharing architecture. And while we discussed this, what came to mind for me is the PCORI's CDRN, the Clinical Data Research Networks, as the very advanced example. And thinking, you know, evaluating an organization on their extent of information commons or information sharing architecture the criteria used to evaluate the CDRN proposals could be really a nice framework for sort of going from low performance to very, very, very high performance. And this would include sort of bidirectional adding and retrieval of data and resources or information for patients and for their care partners, both family and professional care partners.

This seemed to us relevant for all

patients, and we saw this could be sort of a facility system survey and/or patient survey. And this is a sort of system measure. I happen to serve on the CDRN Review Team and it really stood out as a nice example, and the criteria for evaluating those seemed very applicable for this sort of work.

The next example of a measure concept we had was about patient and family engagement and decisions explicitly with making sure that the organization, the institution has clear requirements for patient engagement. And as an example of this, which we're pretty enthusiastic about, is that there would be recertification requirements for providers tied to family engagement as part of their evaluation process. So really, you know, trying to back up to the sort of C suite level of an organization and that there would be this sort of -- a data source could be, you know, documentation of conversations of patient and family engagement and that the institution ultimately would be defining who has responsibility for this sort of measure, but it would be a sort of system-level measure.

So those are the two that I'm going to share.  And then I think both Sally and Annie have one for Concept 4.

CO-CHAIR OKUN:  Okay.  So the one thing that we actually did identify is that this core concept was slightly confounded.  So we had collaborate and decisions in my care and then also I choose the care partner.  So there was a little bit of thinking about, you know, maybe these need to be separated out.

But in any case, the core concept that we went through and what I'm going to present here is the elicitation of preferences for collaborative decision making and sort of getting at the point that not everyone is necessarily interested in participating in collaborative decision making, so that finding some way of understanding what people's preferences around that might be.

So that really does need to apply to everyone. It seems like it's the appropriate question. What methods of communication do you want to have, how do you want to be a participant in the decisions that we need to make together going forward, and what are your preferences around that?

So a few ways that we could do that in terms of data sourcing. One would be a pre-visit input, you know, sort of understanding that here's what we're here to talk about today, how much collaborative decision making -- you know, using different words that would be appropriate for the patient and someone who might be with them to understand here are some decisions we may need to get to today. I'm going to be asking you for your input and your collaboration on them. How comfortable are you with that? So finding some way of being able to do some of that on the way in.

And then being able -- again, I think back to Dave's point; and I think I want to keep repeating that because it's such a good idea, sort of on the exit of the visit how did that go?  Did we get to the things you wanted to get to?

More sophisticated ways of doing some of this might be having some advanced care planning mechanisms where you're actually doing some preference assessment that reflects changing preferences over time.  So that as someone's illness progresses or things change for them that you have a better understanding that, you know, things that you may have thought you preferred early on in this progression of your illness or whatever may seem different today so that we're having an opportunity to revisit that.  And that does need to transcend settings and time because there may be times when, you know, that conversation is taking place in a different environment from where the original decision making took place.

And then shared decision making tools, the results of using those. So how the experience was for patients using a shared decision making tool. Did they find that useful in making their decision?

And one of the feedback loops that I'd love to start seeing with decision making tools, support tools is a feedback mechanism that at some points makes another assessment. You know, looking back did you feel that decision was really reflective of what the outcome was that you ended up getting? So having some way of really testing whether shared decision making tools ultimately lead us when we think in hindsight as to whether or not that actually was something that had --

And I put this in the construct of I hear so frequently had I known then what I know now. So what I want to sort of tease out is do shared decision making tools help patients learn what they needed to know now in order to reflect back on the then when I made the decision with this information and this tool?  I look forward and looking in hindsight say that was the right decision based on what I had, the information I had.

And if it wasn't, was it the tool that was the problem?  Was it that I didn't -- you know, trying to tease some of that. That's complex and complicated, but I do think that our shared decision making tools sometimes -- I think we're depending too much on them being able to be the answer and as something that's going to demonstrate collaborative decision making, but we need to look at what the outcomes are.

So there's obviously system-level measures that would need to be in place, you know, as opposed to just checking a box that we've completed an advanced directive or that we've actually participated in a preferences assessment, that we actually show some evidence of the patient actually having some participation in that. Again, the patient and family participating in the documentation of what their shared preferences are and sharing those with the clinician. So it's putting some onus on the family and the patient to make a decision about how collaborative they want to be. And if they don't want to be, okay, we recognize that. But if they want to be, that we're giving them the information they need and the language they need and those sorts of things.

MEMBER WALLING: Okay. And this part was really -- I mean, I think the concept we had was that the ultimate outcome would be that the care received matches what the patient's preferences are, but then how to operationalize that we felt was pretty challenging. So what we did was we limited the denominator to broadly decedents and may have to be narrowed every further, but we thought that perhaps you could use utilization here.

So for example, ER visits at the end of life. A patient with serious illness, for example, may have decreased functional status and going to the emergency room would likely be a burden and they would probably prefer either care in their home or care with their primary physician. So there may be a role for utilization here.

Other ones that we thought -- we didn't talk in depth to those, so I think there would definitely have to be a lot more talk about it, but ICU days or days in hospice depending on what the denominator is.

CO-CHAIR OKUN: Okay. So we'll open that up for discussion.

MEMBER NELSON: One of the things I had just wanted people to be aware of; it may be helpful, is that there was an article published by Glyn Elwyn and others in 2013 and was in the Journal of Patient Education Counseling. It's a fast and frugal patient-reported measure of shared decision making in clinical encounters. And this is the initial development results that's being further validated.

Their idea was to have lowercase shared decision making rather than uppercase. It's not necessarily the big decision. It's all the little decisions that are part of office practice. And they did a lot of qualitative work and cognitive testing. And as indicated, it's being further validated now.

But what they ended up with was just three items that's meant to be asked, let's say, 8 to 36 hours after a person visits a clinician. How much effort was made to help you understand your health issues? Item 1. How much effort was made to listen to the things that mattered most to you about your health issues? How much effort was made to include what matters most to you in choosing what do next? And so that's the fast and frugal measure. And they believe this would apply to many kinds of regular clinical interactions in an outpatient environment.

CO-CHAIR OKUN:  That is called the CollaboRATE tool, isn't it?

MEMBER NELSON:  Exactly.

CO-CHAIR OKUN:  That's what they named it?

MEMBER NELSON:  Yes, it's the CollaboRATE tool.

CO-CHAIR OKUN:  Kevin?

MEMBER LARSEN:  There are a couple of tensions I think that are on the table that we haven't sort of articulated, and so I'll articulate them, not to say that I have a particular solution.  But one of the tensions that we were thinking about hard at the health system as I left was the difference between relationship-based care and transaction-based care.

So if you've read the work of -- oh, what's his name from the Harvard Business School talking about prescription for innovation that one -- Clayton Christensen. One of the issues that we have in modern healthcare is that we have conflated all healthcare into both models of care, transaction and relationship, into sort of one unit of delivery. And that may actually not really be very efficient or effective. And some of the reasons that we do expectation mismatch is people that are there for a transaction don't want to wait for someone else's relationship to like spill over. And people that are there for a relationship want more time than what that transaction has been scheduled for.

And there are both times when providers want one or the other and times when patient want one or the other. And that really frames, at least to my mind, what you're expecting of an encounter on both sides of it. And so we can potentially add too much to a transaction visit by all this shared decision making stuff when that's not really what you want. So anyway, that's one tension that we have.

The other tension that health systems are facing is this idea of customization versus standardization. And so, you know, we're talking a lot here about how I want all my care customized to me. But we also talk about I want to be held to the highest levels of scientific evidence. I want the best treatment.

And so, again I don't have a solution to that tension, but calling those out as sort of domains of tension often helps me reframe and re-look at these questions and say how broadly applicable are they and are some of my troubles because those tensions are at play?

So I want everything completely customized to me, but I also want the very best scientific evidence. So the very best scientific evidence isn't completely customized to you. The very best scientific evidence says everybody over age 60 should have X, right? And so guideline and cookbook medicine actually is there for a reason because it helps assure that people are getting the best care that we know of in science. And you can build efficiencies of scale around that. If you try to customize each and every one of those things to tailor and fit each and every person, you run out of time, frankly. So you can either be efficient and deliver them as a bundle or you can try to customize it all and never get to all of them.

CO-CHAIR OKUN: You know, it's interesting. That's a great framing, and I think it gets back to a point that Bruce was making earlier. And maybe there is this sort of opportunity to think about the transactional experience versus the relationship experience and having some way for people going into a healthcare encounter or some care encounter of some sort understanding what those are.

And if I'm really just going in for my flu shot or if I'm really just going in to talk with whether I want the shingles vaccine, that I'm focused on that without necessarily having to go into this relationship thing that Mike -- you know, because I really don't want to go into all of that. But it ultimately bubbles back up to, you know, whole person care, too. So understanding that I may be going in for those transactional experiences and that person may not know everything about me.

And so, I think it's an interesting tension, Kevin, and I think it's one that could ultimately need to get teased out where we see measure gaps. The measure gaps may be that we haven't really focused on some of those kinds of distinctions. So that's a great --

MEMBER DEBRONKART: Just a quickie. This is as meta, meta, meta as you can get. It seems to me that this whole endeavor and everything about shared decision making and all of that is a reaction against the discovery that a whole bunch of things were not being done in a way that is patient-centered from the beginning.  I mean, I know the story of the discovery in the beginning by Jack Wennberg of unwarranted practice variation, right?  And so, the whole field of, you know, shared decision making grew out of trying to fix that.  And in fact I imagine there's Wennberg DNA in PCORI, right, because that's what led to the whole idea of outcomes research in the first place, you know, to serve evidence-based medicine.

And now we're realizing that what we need to do is enhance the -- so I'm just wondering maybe -- so I don't have specific advice or requests, but we ought to be sure that we're thinking about how common sense, whatever that is, says things should be as -- and not just limit ourselves to fixing the defects.  Everybody I talk to in my life when

I talk about patient-centered things and all that, they're like, well, aren't they already doing that?

CO-CHAIR OKUN: Well, yes, I think there's some presumption that probably we are already customizing that and if I need a transactional visit, you figure that out. And, no, when I say this to my husband, he looks at me like I just want to go in and get my appointment done and come back out, you know?

MEMBER DEBRONKART: Right.

CO-CHAIR OKUN: I don't really want all this other fancy stuff that you're talking about.

MEMBER DEBRONKART: And then in contrast to that I was on a call a couple of weeks ago where a guy said -- he was talking about medication compliance and he just said flat out the problem is that patients don't do what their doctor has decided is best for them, you know? And it was really good for my criminal history that telephones don't support arms reaching through a phone wire.

(Laughter.)

CO-CHAIR OKUN: I'm going to go over to Jennifer before Ethan. She had her card up before you. Jen?

MEMBER EAMES-HUFF: So I really appreciated the discussion around this really important construct about decision making and wanted to, I guess, raise one concern that I have that relates to my own work, which is focused on older adults with complex health needs who often rely heavily on another person to both enact their care plan, but also to communicate with health professionals. And it's not an insignificant number of older adults who really delegate decision making to another person. This also is relevant in terms of hospital decision making.

There is a paper that was just published this year by Alexis Turgeon in Archives of Internal Medicine looking -- and she found that 50 percent of hospitalized older adults relied on a surrogate decision maker for very important issues around life-sustaining treatment.  There's a large literature showing that proxy decision making also can be very burdensome when proxy decision makers don't know preferences of individuals.

So I would like to put this out there for the transcript and for further reflection with the idea that perhaps NQF might consider measure development around the extent to which family care partners are included in the collaborative decision making process and also for measures around, you know, sort of looking at a system level about collecting proactively information about patient care preferences in the event of an emergency.

CO-CHAIR OKUN:  I want to also come back to something that Gene had mentioned, too, that oftentimes while you're

-- I think you're mentioning in some regard some of the more important -- not, you know, that those aren't important, but some of the major decisions that need to get made. There's lots of decisions that are being made on a regular basis by proxies for people on, you know, things that may seem less consequential but equally important in the quality of life of someone.  So I totally agree.

And the other thing I wanted to just come back to because Chris wasn't here to expand on this, but the information commons concept was really having some opportunity where people could be given information or access information.  And some of that would be patient-generated information, so it would be the concept of here's how it worked for me. Here's how it might work for you.  Sort of really giving people access to things that that would give them better decision making opportunities that don't depend solely on the system, right?

MEMBER BASCH: Yes, thanks. Just a quick comment. You know, in order to collaborate in decisions people have to understand the goals of care. And there is evidence suggesting that oftentimes people walk out of the office and there's a disconnect between their understanding of the goals of care and the provider's understanding of the goals of care. And there's one very nice paper from about a year-and-a-half ago from Jane Weeks in JAMA -- or actually the New England Journal where a data set showing that the majority of patients with incurable metastatic cancers believe that the goal of chemotherapy is cure, not palliation.

And, you know, the logical extension of that is that their decision making process is -- you know, the balance between risks and benefits is probably off because people don't understand the goals of care. And, you know, that doesn't necessarily point to a failure of the providers to explain the goals of care. They very well may be. We don't know. But it's a broader system failure to assure that patients understand what the goals of care are, you know, in order for them to make decisions. So I do wonder if, you know, there's a piece of that here, if there are some mechanisms for assuring that patients actually understand what are the goals, you know? And that extends beyond advanced cancers, I think.

The other brief comment that I was going to make is that I think transactional care can still be, you know, thoughtful and humanistic and, you know, compassionate. I like my accountant to be friendly.

(Laughter.)

CO-CHAIR OKUN: Yes, I think we're still suggesting it be humanistic, but it doesn't necessarily need to be as relationship-based as some of the other types of encounters might need to be.

MEMBER LARSEN: Yes, and I think the sort of striking example for us is we had a Joint Commission requirement to do things like screen for domestic violence. And when someone was there for a purely transactional visit, even if it was friendly and patient-centered, they often felt intruded upon with a laundry list of these really personal screening questions. Now, maybe that was the right thing from a public health standpoint, but it was really not meeting the expectations of the patient that came for a really short transactional visit. Give me my flu shot. Why are you asking me if I'm being beaten up at home and how much alcohol do I drink?

MEMBER BASCH: I mean the joke in North Carolina now is, you know, the provider says to the patient, you know, do you have a gun in the house? And they say, well, I don't. Well, why not?

(Laughter.)

CO-CHAIR OKUN: Well, all right.

I think then -- Gene, did you have a comment?

(No audible response.)

CO-CHAIR OKUN: So I don't see any more cards up. So, okay. So I think we'll move on in the interest of time again and in trying to keep ourselves on some time frames that we can get through everything before we're done today.

So we're going to go to Group 4. And Troy was the leader and Wendy was the staff member. So, Troy, do you want to introduce that for us?

MEMBER FIESINGER: Sure.

CO-CHAIR OKUN: We're doing Nos. 7 and 8.

MEMBER FIESINGER: Okay. Sorry. I'll use the microphone. Let me start over.

We do have a little bit left to say. It hasn't all been covered, but it's great to see the overlap because we had many of the same discussions.

So we basically broke these up.

Each of us took one or two.  So, David, you have the biggest time commitment, why don't you go first with yours?  And then we'll each cover measure-by-measure.

MEMBER DEBRONKART:  I'm pretty sure I did it wrong.

(Laughter.)

MEMBER DEBRONKART:  So if you want to do No. 8 first, then I'll -- or I can just go plunge ahead and get --

MEMBER FIESINGER:  I would say go for it.

MEMBER DEBRONKART:  Go for it? All right.  So I'm really uncomfortable here, but what the heck?  All right.  What's --

MS. PACE:  You can just tell us the measure -- you know, the main thing that you think should be measured, or the discussion about what should be measured.

MEMBER DEBRONKART:  So, all right. Well, the patient's experience of -- a patient feeling about providers caring about their time.  Okay?  And for which patient should be included?  All.  But I think it will be useful to segment the data by condition and by acute versus chronic and by overall health status, because I expect there will be significant differences.  Somebody with a bigger disease burden or visit frequency would be more affected by a good customer attitude.

I mean, I know, you know, during my cancer when I would have to come in to the city and then wait an hour-and-a-half for a CAT scan, you know -- and after the first six times you do that, it gets annoying as opposed to a one-time offense.

And the data source, the only thing that makes sense to me for that item would be a survey, you know?  Now, for other things like elapsed time from appointment time to end of visit, that should be collected in the system.  But if I'm picking only one item to talk about, that's it.

And whose performance should be

measured? What I wrote down was the provider system as a whole, but it seems to me that the individual department or practice -- I mean, there's wide variation within Beth Israel Deaconess between departments. So I think probably wherever there is a manager who has accountability and control for that group, that's the level where it makes sense. Now, it may be much easier -- the thing about measuring like the whole hospital is you just -- not only do you end up with an average of everything from A to F, but you also fail to identify the bright spots, you know, where people have solved the problem.

I just found out via Twitter -- you know, I tweeted isn't there some place that has eliminated waiting rooms? And somebody came back within five minutes and said, yes, Virginia Mason. So once again, we come down to, look, you guys, it can be done. And so that's why we want to find the bright spots. It's not all of Virginia Mason. It was a particular clinic.

CO-CHAIR OKUN: And to Kevin's point, I think, before, where there are some really good things being done out there, we need to illuminate them and raise them up and support them and find ways of scaling them, right?

So I guess the question I would have, David, right away would be where do you see the patients measuring this? Was this in your --

MEMBER DEBRONKART: Where do I see the patients measuring it?

CO-CHAIR OKUN: Yes. So you're thinking about measuring as a systematic whole, but also at the department level. And so where is the patient input on that?

MEMBER DEBRONKART: Oh, it was the patient-reported --

CO-CHAIR OKUN: Okay.

MEMBER DEBRONKART: It's a survey.

CO-CHAIR OKUN: A survey? I'm

sorry, I missed that part. Okay.

MS. PACE: Troy, would you explain -- I think this is about the time concept, isn't it? My partners value my time?

MEMBER FIESINGER: Yes, No. 7. Partners value my time.

MS. PACE: Okay. Right.

MEMBER FIESINGER: Okay. Sorry. This was clear yesterday afternoon. Maybe, Wendy, the email that you sent, is there a way to display that? Paste it into a slide?

MS. PRINS: Yes, I could do that. Oh --

MEMBER FIESINGER: Did you have a suggestion, Mark?

MEMBER NYMAN: Should I build on those comments a bit, too? And I think we really just had one concept for this particular core concept. And if we use that same idea of respectful communication, culture, environment, you could summarize this as respectful of my time. And we did have several different outcome -- both process and outcome measures that we mentioned. And some of them actually are already being measured, so like your wait time in the ER and wait times for appointment, but we also talked about wait time for hospital discharge. And a question like do you feel like they cared about your time?

Another question getting to kind of what Maureen had said is just making me aware of why there's a delay. So I'm okay with waiting a little longer if I know that the doctor has spent more time with the patient before me, but just to be -- so that's being respectful of my time if you let me know why I have to wait.

I mean, actually the way that the core concept title is, it would be a great global question for this and that's, you know, my care partners valued my time and used it efficiently and effectively. That kind of would summarize the whole thing.

We didn't talk a lot about this, but I think this particular core concept is informative with regards to all of what we've been discussing today because we keep talking about how we want to measure or get feedback with regards to how well we're doing using patient-reported outcomes.  But to be respectful of people's time we're going to need to be very careful about how many questions we ask them.  And so, you know, as a system-level if you're using the SF-36 versus the PROMIS-10, that might be an indication of how respectful you are of their time.

But we had also discussed that -- or today there's been discussion about the granularity of, you know, is it the provider or is the desk or, you know, what part of the care thing?  Right now when I get provider feedback as a general internist, they send out the survey several months after and they say specifically, you know, what was the care like that Dr. Nyman delivered? And then the comment section will say the ENT physician didn't listen to me. You know, so the feedback we get isn't really specific, but then in order to drill down specifically, we'd have to ask a lot more questions. So I see that we have a bit of a conundrum and a challenge with this particular measure.

MEMBER FIESINGER: An additional comment. I was in the group, too. I'm a champion of treatment burden as a measure and some part of treatment burden is respect for my time. And I think treatment burden is something that we didn't actually -- it doesn't have a good home very effectively in our current construct. There wasn't a great place to say this is where treatment burden goes.

MEMBER WOLFF: So just to jump in, I know Bruce would agree with you entirely. And we had a sidebar conversation that treatment burden was not explicitly touched on in any of these constructs, but potentially does fit somewhere in 2. So that's a great addition, just to --

CO-CHAIR OKUN: And can you expand on what you mean by treatment burden?

MEMBER FIESINGER: Sure. So imagine that you have a shared care goal with your provider and there are five options, and those five options have a slight variation in potential outcomes and they have variations in cost, but one of them makes you come to the doctor's office every day for the next three months and have five lab tests a week. And another one is a pill that you take at home. Same cost. Same statistical care outcome. Maybe similar relative amount of evidence behind them. And so there's the treatment burden. That is the burden to me as a patient for this particular treatment versus a different treatment. And, you know, quality-adjusted life here doesn't exactly get to it because it's very specific to a certain treatment regimen.  So you can imagine cancer treatment options.

Another keen example in this is the new treatments for -- instead of anticoagulation with Coumadin, the newer -- that requires a lot of return visits and blood draws to the hospital, but it's an old cheap medicine.  There are new expensive medicines that don't require all that.  And so the overall cost to your health plan might be the same or even higher for the new pill, but to you as a patient the burden of visits and blood draws is dramatically less.

CO-CHAIR OKUN:  Okay.  Thank you. I am wondering whether some of that might be addressed in No. 6, too.  So as we move forward we can keep an eye on that one.

MEMBER FRANK:  Well, and it did come up in No. 8 in that part.

CO-CHAIR OKUN:  Okay.  All right. So, Gene?

MEMBER NELSON:  I liked Mark's

comments.  One of the thoughts I had again sort of short-term/long-term and towards measurement is just as there's the PROMIS-10, which is quite useful, at one levels we heard yesterday there might be the Person-Centered Care 10 as a starter that is rather global and up a level and accommodates the domains underneath.

MEMBER DUBOW:  I liked Dr. Nyman's comments also and it made me think of two things, and that is survey burden.  We know that CAHPS rates are going down, not up.  Used to be very robust responses.  And we're seeing the more we ask questions, the less inclined people seem to be to participate.  But, you know, the business about somebody -- and this speaks to the actionability of the information we can get from the instrument or the question.  It has to do with how much somebody wants to disclose about the experience with that ENT and how they feel that information will be used and whether they will be able to have a comfortable conversation with the provider about whom they are critical.

And I just think we need to take into account those kinds of sensibilities when we think about what we're asking people and how we help them understand how this stuff is going to be used.  So it's both survey burden and issues around privacy and preserving, protecting confidentiality of the information.

CO-CHAIR OKUN:  I wonder --

MEMBER DUBOW:  And actionability.

CO-CHAIR OKUN:  Talking about the fact that, you know, the CAHPS scores or the survey responses are going down, maybe that's an opportunity to look at, you know, why.  Are they just not really giving people the opportunity to give us the data or the information that they want?  And does the Patient-Centered 10, possibly, become something that could attend to some of that so that it actually gets a bit more personalized and customized?

MEMBER DUBOW: I think that's a research-able question, but I don't think we should assume it's just because people are being asked CAHPS. My personal opinion is that that's not the case. I think we're bombarded with surveys. Now I can see my own response every time the telephone rings.

CO-CHAIR OKUN: No, I actually totally agree.

MEMBER DUBOW: So I think we shouldn't be under any illusion that people are really eager to provide this information. I think they generally find that, you know, this takes time and people -- every time a friend or a relative gets a CAHPS survey, I urge them to respond because I'm so aware of the declining rates. But I think it's a research-able question.

CO-CHAIR OKUN: Thanks.

MEMBER FIESINGER: So I'm going to step and I'm going to take another run at introducing our group. So it might be easier with this email. So we basically took Concepts 7 and 8. They tended to blur together a fair bit. We voted on basically five measures. I think the first one we just talked about. Right information, right time, right patient. Second, my time was respected. We just talked about. The patient perception of communication quality, care team to patient communication bidirectionally and then information access. So that's what I should have said about five minutes ago. So now you have it.

And Dr. Nyman has already talked about was my time respected? We tend to take a more global view of these things and we try to think of those concepts. So some of this I was a little rusty on the measurement, but I really tried to get what's the feeling we're trying to capture?

MEMBER CONNOR: I appreciated Mark's comments about explaining to patients why they are delays and communicating this effectively. What we learned from our patients at Dana-Farber was that they didn't mind as long as we communicated with them. And in fact, we had a sign on the desk if you've waited longer than 15 minutes, please approach the facilitator.

So we initiated a QI team to work on wait times. And per usual we had a patient and family member as members of our QI team and we learned from them that patients and families were reluctant to even ask the facilitator because they did not want to bother her. They thought she was too busy and they didn't want to be a nuisance. So I like this story because it points out the value of having patients and families on QI teams. But at any rate, that's --

MEMBER DEBRONKART: Yes, and the one time I did that in my primary practice, the woman kept looking at her papers and then looked up. She didn't know why I came to the counter. Why are you telling me?

MEMBER FRANK: Yes, so I just wanted to make the point that there was a lot of blurring between 7 and 8, and this was a good example. So this came from the idea of airplane passengers on the runway. We know there's going to be delays from time to time. Same in the healthcare system. But please just give us the information. But so we weren't interested then in endorsing a measure about everything happened on time. It's just when there are glitches, the information is provided back.

MS. PACE: So are you saying that you took off the table a measure about being on time? I'm just curious.

MEMBER FRANK: Kevin was in our group, so, no, that didn't come off the able.

(Laughter.)

MS. PACE: I mean, because in the airline industry they still do the on-time percentages, right?

MEMBER LARSEN: Of course they do.

I mean, and to be fair, I was telling Ethan behind the scenes, we measure things that we're not satisfied with and many measures we don't expect 100 percent. So part of the trouble in healthcare is all of us are used to being A-plus students.

(Laughter.)

MEMBER LARSEN: And so we all want measures that we all can get A-pluses on when it turns out that maybe sort of the best possible system performance in the U.S. is a 70 percent. But we're never going to get the 30 percent people to improve unless we're all measuring in the same way and you can actually see that there's someone able to achieve 70 percent.

MEMBER FIESINGER: To me I think that's an example and what I've used and ideal would be a partnership between the patients and the caregivers.

For example, my Thursday clinic I ran behind because I worked on an 86-year-old who had a CHF overload because her daughter gave her three slices of Red Baron's pizza for her birthday.  So we needed to talk about that and I needed not only to treat the CHF, but also tell her daughter, look, it's okay.  You didn't kill mom.  Because she felt awful.  And by the end of the day I've got the Spanish speaker and when I'm tired my Spanish gets bad and I can't translate as quickly in my head.

So my thought was a way to respect the time is to have that conversation.  Yes, I'm running behind, but here's why.  If you have to go pick up your kids at 5:00, can we see you sooner?  Can you go home?  I'll do an e-Visit at 6:00.  I don't mind.  I'm still doing charts.  A way to have an open partnership between everyone, because in my practice we all know each other and you know these patients very well.  And patients will roll with a fair amount of stuff if they understand.

My favorite line a mentor of mine

said is next time it's your emergency, I'll put you first. Because his patient said, okay, Dr. Reese will treat my emergency. And when I had to run out of the clinic to deliver a baby, the people are like, oh, great, tell us if it's a boy or a girl as I'm doing a prostate exam because I've got to like leave in the middle of it.

(Laughter.)

MEMBER FIESINGER: So but if you have the openness and transparency, a lot can be overcome. So I want to find a way to measure that.

CO-CHAIR OKUN: Yes, I actually think you raise a really good point, and that's the perception of urgency. So my perception as a patient sitting there and knowing I have 10 other things to get to do that afternoon and you're holding me up from getting to those, my sense of urgency about my need getting need is one thing. Your sense of urgency over the patient who you're sitting with who you clearly have a clinical need to deal with is another piece. And so, that information sharing I think is really an important piece.

The other thing, and this may be sort of silly, but I'm just wondering whether or not there's also some attention paid to providing people something other to do than just sort of sitting there waiting for you. So that could be the information commons, you know, having some ways within your environment where you give people access to something other to do other than sit there looking at the clock.

MEMBER FIESINGER: So currently we're actually doing that. We have video monitors, patient educational videos. I tend to run behind. I send people to the lab first and then see them afterwards. I try to get couples together as much as possible. We're actively looking at that in our practice. So I think that's an excellent way to use their time valuably. And my patients know also bring a book or bring your laptop. Use our guest wireless and do your work while you're waiting.

MEMBER NYMAN: Just to follow up on survey burden, I think if patients see that we're using the answers to either help them or to change our practice, they'll be more encouraged or willing to fill these PROs out. So I think how actionable are questions and answers and do we act on them I think will be important.

MEMBER FRANK: Yes, I just wanted to add that we did discuss in relationship to this last set of concepts distributive justice. So, you know, we do want to always deliver to patients, but at the same time there are other demands. And was the patient informed about what the system level demands are so they could better understand.

MEMBER NELSON: One of the things that is being learned is that if you give people a choice of how to respond to the survey -- so it's my smartphone, it's paper and pencil, it's a speech-enabled IVR, it's at home on the Web, it's the touch pad in the office. Multiple channels that match the person's preference goes better and you get much better response rates and people are more willing to share their information with you.

CO-CHAIR OKUN: That's a great idea. Kevin?

MEMBER LARSEN: Yes, just a little more in-depth on item No. 1. I think it's really a key one and this is where care coordination and communication really I think blend in this right information at the right time in the right format. And so, a provocative measure concept that I put forward was when I get to a care transition all of my information beat me there and was read and used by the next provider before I entered the room.

And so, those kinds of sort of

future-looking provocative ideas of really what we set as high expectations for each other as partners in care I think are the types of things that move this forward as opposed to just some perception where people will be based on what their current experience is, which is so universally not the ideal, that our expectations are so low that we are okay with measures that measure things that are actually not what we want.

MEMBER DEBRONKART:  A quick note for the record.  This isn't part of measures, but there's something new coming along that came up in our group yesterday, which is consumer-friendly bits of information. There's Meditoons, M-E-D-I-T-O-O-N-S, these soundless videos that you can watch in the waiting room.  YouTube length, one or two minutes.  Also Khan Academy now is doing all kinds of high-quality medical training things. And in my ideal world a clinic would have -- like I would be able to log in on an iPad or a kiosk in the waiting room and it would record in my chart that I'd watched this, this and this so that the provider would be informed that I'd gotten some information.

CO-CHAIR OKUN: I like that. The other thing I wanted to also be sure of is that we're using people's times ahead of a visit effectively so that they're given the opportunity to not waste time having to complete something. If there's anything I hate more it's going in and saying, oh, you have to update this. Well, if you had just given me that, you know, ahead of the visit, I probably could have done that ahead of time. So those are other ways. Doesn't cost much more to, you know, kind of take that time.

MEMBER FIESINGER: So, to elaborate on what Kevin said, my view of the right information, right time, right patient is what he's talking about and to me it's a concept of not just the patient but the providers. Definitely as a family physician

I'm sure any of the general physicians in the group can allude to this, and the specialists. If you don't have the specialist's report, you don't have the hospital imaging report, whatever, you waste not just the patient's time, but your own time. I've got to go back and look at it later. And on a business sense, that's uncompensated and it's a pain.

To me the goal of the center should be everything is there, right there to take care of the patient, make the decisions, resolve the problem and we all walk out and we're all done and everybody's happy. And I think that's the goal we should push the system for and where it helps is if a problem isn't me and it's say some specialist, I can go to them and say, hey, I'm getting dinged on this measure. Guess what, this is you, buddy, and we need to figure out a better way to make this happen. Or I go to the CEO. Same thing. We're getting dinged. We need a system approach to this.

CO-CHAIR OKUN: It does feel like a shared accountability kind of measure being able to be sure that, you know, where I'm performing seems to be okay, but what's happening is that I'm getting dinged because of something else in the system that I don't have control over.

So I think I missed Gene. Go ahead.

MEMBER NELSON: I think it's come up a couple of times; Dave mentioned it, having a very simple question after an encounter. And there are a couple of groups working on an item in effect that asks the person please tell us in your own words what went well and/or what can be improved. And it's in their own words. And then that is put through a speech recognition and categorization algorithm and it can give you in their own words what people really say as well as can be mapped to the kinds of domains that we're talking about.

And it's possible with like a single item that's structured plus that to get perhaps almost as much as you would get with a 10 or 20 or 30-item survey. And it's all with self-customizing, but it can be analyzed in both a structured and an unstructured way. So it's something that's under development. There's been a few articles on it. And I think it's a very promising way of thinking about getting more information, more localized. It's sort of like having a running focus group. And it's always coming at you in their own words.

CO-CHAIR OKUN: That's great. And I think what it reminds us of is that we need to be thinking that the technology will be rapidly advancing ahead of some of the things we're talking about here and that we need to be sure that I think in all of the things we're talking about is maximizing the technology available at the time and envisioning technology capabilities that we may not even have yet. So, that's important.

MEMBER RADWIN: I was wondering if the group addressed at all this idea of multiple appointments all on the same day as being respectful of time. The system I'm in one of the reasons it's so cost-effective is because only certain centers do certain things. So people will travel from Maine -- well, Maine is a bad example -- Manchester, New Hampshire down to West Roxbury in order to have surgery. Or my favorite example is daily radiation. They have to travel to Jamaica Plain in Boston, which is quite a hike. They can stay in a domicile there, but when you're sick, that's tough. And I'm just wondering if that came up in discussion because it's a particularly intriguing idea to me.

CO-CHAIR OKUN: So are you suggesting that while they're there for the radiation that they may be having other appointments as well?

MEMBER RADWIN: No, well, but it's

the distance and time.  Just hold that example aside.  So ophthalmology clinic is held in JP on Wednesdays.  And the dermatology clinic is held in JP on Tuesdays.  And this whole idea of -- but this is not unique.  I mean, I'm not a vet.  I'm don't my care there.  But I can't get my mammogram and my Pap on the same day. I have to keep coming back.  So that's my question is is the group handled that at all.

**MEMBER LARSEN:** Yes, so when we talked about this, respected my time, we gave it a sort of concept header, but at least in my opinion, operationally there are probably two key separate operational streams, and one stream is a patient perception of time respect and another is actually system measures that you can just derive out of data from the system.  And so we had a number of those things like waiting time in the emergency room, waiting time in the clinic waiting room between check-in and when your maybe first vital signs are taken or something.

But I think these kinds of things, just like what Dr. Holly was talking about yesterday, could also be measured, which are the amount of -- the sort of frequency of visits that are spread across a calendar month as opposed to how often do they appear to be coordinated.  And you could actually get administrative data in most scheduling systems and construct a measure around how much things are focused and coordinated on specific days versus how much is there sort of scatter shot at the convenience of the institution as opposed to the convenience of the patient.

CO-CHAIR OKUN:  Okay.  I want to take a time check.  Karen has a comment.  Dave, did you have another comment?  Are you all set?

MEMBER DEBRONKART:  (No audible response.)

CO-CHAIR OKUN:  Okay.  Troy?  And then we still need to discuss No. 8 in your group, right?

MEMBER FIESINGER: Yes.

CO-CHAIR OKUN: Okay.

MEMBER FIESINGER: So we have two more measures to discuss. I just have a comment and then we got the second two measures.

CO-CHAIR OKUN: Okay.

MEMBER FIESINGER: Do you want my comment now?

CO-CHAIR OKUN: (No audible response.)

MEMBER FIESINGER: Well, okay. I'll say it. Sorry if I went out of order. So the way I would think conceptually of this respect for this time was this is a tiered trigger measure, meaning if you get a great score, great. Don't go any farther. If you get a bad score, now you got to drill down into the why is it? Wait time for the doctor. Wait time for radiology, lab, to get the imaging test ordered. Is it that appointments were scattered across time and space? So you can drill down at a lot of minutiae, but to me as a provider I would like some simple metric that I can start with and then move from there as I go through my practice improvement process to figure out where the problem is and how do I improve that global metric.

MS. PACE: And I just wanted to make one comment on, you know, informing people about the reason for delay or giving them other options. I think the other thing to at least consider is what Dave brought up yesterday about tweeting people that there is a delay, so that they can maybe stop at the grocery store or, you know, do an errand before they come and sit. Or also, if it's going to be a long delay, giving them options like do you want to sit here and wait? Do you want to reschedule? So I think it's also giving them some choices of how to respond to the delay that I think would be helpful to people.

CO-CHAIR OKUN: And I think

because this has come up before; and Bruce isn't in the room, I want to be sure that we recognize that the same kinds of things need to be considered for home care and for environments where someone's waiting at home for a long while and not getting updated as to someone coming in.  I am remember my own experience with my mother-in-law going home from a hospitalization and they said, well, they will there at 10:00 the next morning, and they didn't show for two days.  But, you know, the fact was we at least were there and we knew that we were expecting it, but no one was giving us any feedback information.  And so it's just again being sure that we're mindful across settings here is going to be an important consideration.

Okay.  I'm mindful of the time, so, Troy, you want us through the next part of --

MEMBER FIESINGER:  Okay.  Just let me pull my notes up here.  Sorry.  Everything locked up while I was talking.

Okay. So the last two. One is patient care team communication, and this is the patient to the care team, care team to the patient. And our brainstorming was does the patient understand and comprehend the key points cross-sectionally and longitudinally? Was patient's understanding of those points evaluated? Do you feel like you know what to do before the next visit, appointment, next day, hour, etcetera? So I thought of this as a process measure. And it can look at patient education, goal setting, next steps. There are a lot of nuances to this. You can decide how granular you want to get, but really a process.

Which patients should be included? Everybody.

Data sources. Patient survey. I don't know if Press Ganey or CAHPS had this specifically. I'd have to look. But the Ask Me 3 campaign came to mind where the questions are:  What is my main problem?  What do I need to do?  Why is it important for me to do it? A fourth one I might add, by when do I need to do whatever I'm supposed to do?

And who should be measured?  To me it would be the care team.  That might the clinic.  It could be at the hospital, at the facility, etcetera.  But it's whatever group of providers is carrying for the patient meaning multiple team members can provide that evaluation, that service.

CO-CHAIR OKUN:  Okay.  Shall we move on to No. 8?

MEMBER FIESINGER:  Sorry, that is Concept No. 8.

CO-CHAIR OKUN:  Great.  All right. I'm sorry.

MEMBER FIESINGER:  We kind of rewrote the rules on how we organized things.

(Laughter.)

CO-CHAIR OKUN:  That's okay.

MEMBER FIESINGER:  This did relate

to Concept No. 8.

CO-CHAIR OKUN:  I wanted to make sure I didn't miss something.

MS. PACE:  So on this that we're displaying, that's No. 4, right?

MEMBER FIESINGER:  Right.

MS. PACE:  So what about --

MEMBER FIESINGER:  So care team/patient communication relates to Core Concept No. 8.

MS. PACE:  Right.  And what about this No. 3 and No. 5?

MEMBER FIESINGER:  So No. 3 relates to Core Concept No. 8.

MS. PACE:  Right.

MEMBER FIESINGER:  No. 2, my time was respected to me, is Core Concept No. 7. We thought mostly the right information, right time, right patient, No. 1, related to Core Concept No. 8.

MS. PACE:  Right.  Oh, okay.

MEMBER FIESINGER:  You can maybe

say a little bit to timeliness. This is where it got fuzzy for us in our minds.

MS. PACE: Right. Sure.

MEMBER FIESINGER: And we just lumped it all together.

MS. PACE: Okay. And what about this information access one?

MEMBER FIESINGER: No. 8.

MS. PACE: Okay.

MEMBER LARSEN: And a little bit more detail on the information access. It isn't just clinical notes. It's really is this a practice that or a care provider that's transparent and all the information is available to the patient when and where the patient wants and needs? So there is not an us versus them Great Wall of China between my own information within their organization and my access to that side.

MEMBER FIESINGER: So I'll elaborate on that. Sorry. So basically what he said. You know, complete transparency is open.  It's there.  It's available.  And again it's bidirectional.  The patient can import information that I can read.  I can put information they can read.  I can put documents there that they may need to review. They don't have to call and ask what I what I told them.  The classic, "Can the nurse tell me what the doctor told me that I forgot because my eyesight is too bad to read the paper he gave to me?"

But, you know, Dave had a suggestion to make things easily open both directions, whatever the information is. Education, test results, doctor's instructions, whatever.

MS. PACE:  Great.  And just to go back to the label concept, it seems like something like this could be in a label in terms of the category might be, you know, access to records.  And then, you know, there could be specific information about is it all? Is it just lab tests?  And I was just wondering if you had any conversation or thoughts about that.

MEMBER FIESINGER: So this may be an answer to your question, and if not, I'll try to answer it. So I thought of this as a structural measure. Basically to think of my clinic, we have a patient portal. Do you have it? What does it do? So really it ties into existing meaningful use and PC measure criteria, which I'd have to review to see which items specifically. But basically you'd have to prove is the portal there? Can you look up labs? Can you look up tests? Can you look up patient instructions? Can you look up clinic notes? You could go as far as -- you don't have to get into the whole open chart concept. That's still a little controversial. But we create the framework for that, open chart being an answer to this measure.

CO-CHAIR OKUN: I'm struggling with something that actually came up in a couple of other conversations yesterday, and that's the notion -- when I think about time, the notion of a 24/7 clock and, you know, how accessible -- you know, being sure that whatever we're including in these two core concepts that there's accessibility when I need it, too.  So and that may be under 2.

Yes, and I think if we're looking at an information commons if we're looking at a PHR, if we're looking at ways for people to get access to information, that's important and it needs to be available 24/7 because they may be up in the middle of the night thinking what did that nurse tell me again?  So I guess that's the sort of piece.

So when you said that about, you know, what did the nurse tell me to do, the presumption would be I would find that on the PHR.  I wouldn't need to necessarily talk to that person?

MEMBER FRANK:  Yes.

CO-CHAIR OKUN:  Okay.

MEMBER FRANK:  So we talked about

both active and passive communication channels and making sure that information was available when the patient was ready for it as well as when they needed it.

CO-CHAIR OKUN: So that would then lead me to then say so it's available and it may be available in an active way by being able to reach someone who can answer my question. And if that's not available, there's a default mechanism where I can possibly get that information in a passive way so that I'm not left with no information?

MEMBER FIESINGER: Right. I mean, so, yes, again thinking of my system, you'd need tiered levels of information urgency. For example, with our email we clearly say if you're having a heart attack, please don't email me because I won't see it until tomorrow.

(Laughter.)

MEMBER FIESINGER: Go to the emergency room. But if you think you have some heartburn and you're not sure, email me, but know I won't get it until I get into the clinic the next morning. But if you just want to know what the care instructions were, you can look at that. You've got it. And then you don't have to email me at all.

MEMBER LATTS: Can I make a comment? This is Lisa.

CO-CHAIR OKUN: Please do.

MEMBER LATTS: So this is a very interesting conversation and very relevant to many things and I wanted to use a small vignette.

So, on regular basis the EHR we have here in Colorado at the University of Colorado, labs are posted immediately to the patient portal. So a patient can go in and see their labs immediately. So, you know, being the doctor I am, I check my labs very regularly. I know exactly when they're done and I go check them and I know them before my doctor. My mother has the same EHR in

Minnesota, but her labs don't show up until her doctor releases them, which takes two, three, sometimes four days. It makes me nuts. And she wants to know. And the doctor has to have time to review the labs and then decide to release them.

And I know not everybody is at the same level of sophistication, but the ability should be there for the patient to say I want this access or I don't and let them have the ability to see if they want to be able to see it.

CO-CHAIR OKUN: Excellent point, Lisa. I think there just needs to be -- that's a policy level at the institutional setting, I would suspect. So it wouldn't be something at a state level that would say that you can't release --

MS. PACE: There are some state laws. I go to LabCorp across the country and they'll say they specifically have a list of states where you either have immediate access

or it waits until your doctor releases it. Now, I can't remember the percentage, but they give you a list and tell you that that's going to govern -- at least that's what they're saying. I haven't checked. I thought there were
some --

MEMBER LATTS: That's crazy.

(Laughter.)

MEMBER LARSEN: So, Lisa, I agree with you that most of this actually turns out to be organizationally-driven. ONC has worked a fair bit with this and there's actually a new FDA law that asks commercial labs to release all lab results to consumers. But the implementation has come up straight against the cultural expectations of healthcare providers which are different than the expectations of consumers. And so that plays itself out individually across healthcare systems in a very heterogenous way. So I think having some consistency of measurement so a consumer could make choices, so your mother could pick a different health system if she wants, because she could see that this is something important to her and that another organization has made a different set of choices.

MEMBER LATTS: Yes. Oh, I just wanted to say that I think that's exactly it. You know, part of the person-centered is that the person should have the ability to opt in or opt out or have some intermediate solution.

MEMBER DUBOW: I have concerns when there is a regulatory requirement to do something to put it into measurement. I think this is an issue around enforcement. You know, it's the same thing when people have access to their medical records and are given a hard time in getting it. You know, it's a law. And I don't think measurement should be the tool, because it's too light a touch. If you're entitled, you're entitled. And if there's a violation obviously we have to figure out -- so there should be a complaint mechanism to see that you get your stuff.

I know you're going to pounce on me, Kevin.

(Laughter.)

MEMBER LARSEN:  No, no.  I would say that if AARP would ask the FDA for some help with --

MEMBER DUBOW:  But then on that, we commented on that requirement on lab stuff and I read with interest the pushback from the clinical community.

MEMBER LARSEN:  Yes.

MEMBER DUBOW:  So don't put it on us.  You guys --

MEMBER LARSEN:  No, I'm not putting it on you.  I'm not putting it on you. I'm saying that that enforcement -- there's a lot of things to enforce.  And so, people make decisions about which things get a lot of enforcement and which things don't get a lot of enforcement.  And so, it's the consumers that are really going to be in the seat here to help the Government say this is an area we really, really need enforcement.

**MEMBER DUBOW:** Okay. But, you know, I think that the measurement space and the quality space is a very tenuous space and we want to encourage people to use this for the right purposes and it should not be to ensure that they get their legal rights enforced. It should be to inform them to be able to make choices to help their clinicians make better decisions. And we worry about burden and all of the other challenges in measurement. So I think we need to be very, very judicious in terms of, you know, the areas we measure and our expectations of the measurement enterprise. You know, we cannot be all things to all people and we can't solve all of the ailments of the healthcare system. Lots of opportunities.

**MEMBER LATTS:** Joyce, I agree with you. At the same time I think that part of the overall program, the comprehensive approach to this could be a look at what are potential barriers to persons in our care. And one potential barrier might be legislation or regulation that inhibits the ability for a consumer to make choices. I mean, I agree. It's not NQF's role, but it is part of the approach to person-centered care is taking a look at what are the barriers out there. And if legislation is a barrier, it should be called out.

MEMBER LARSEN: And the other thing I'll say is that there are some floor expectations for what information is available that are regulated, but there are some best practices around the country that go far and above what the floor expectations that are regulated.

So for example, in the State of New York, patients can log in to the Health Information Exchange and see all of their information across the whole of the providers that are exchanging information in the State of New York. There's no regulation that requires that, but that's something that's available to citizens of New York through that tool. Other places like the Geisinger Health System has this open notes concept where all of the clinicians' notes are openly and freely available through the patient portal.

There is no demand, no regulation that requires that, but, boy, that might be the kind of things that different institutions could -- well, maybe it doesn't need to be regulated, but it's the kind of thing that you could imagine Lisa's mother making a conscious choice about I want an organization that releases my labs instantly and that gives me open access to my notes. And by her having that information, she's now in a much better place to choose a provider that's met her goals and expectations.

CO-CHAIR OKUN: Troy? And then we're going to finish up this --

MEMBER FIESINGER: Okay. So to me, I see a measure on this as addressing all these issues, and that if we can measure patients' perception of access to information, we can highlight the issue. Individual patients can decide which practice to choose. Practices can decide what level of openness to pursue based on their demands of the patient.

For example, we had this discussion last week in our group. One of our junior partners said put it all out there. I thought of my mother who reads the lab results and sees low-normal and calls me and asks me why the doctor said it was normal when it's low-normal. My mother has an anxiety disorder. This is what you do. And that's my very biased N-of-1 hesitance to be totally open, but I could be wrong. And if the majority of my patients say we want it, okay, but the quid pro quo is going to be now we got to figure out how to deal with when ALT is a problem or not.

So the measure to me shines a spotlight on the issue and then there's some flexibility in going where you are.  And I do agree with regulations just need to be enforced.  I don't even know how Texas law would affect this, but I'm sure we'll do it in a different way just to be difficult.

(Laughter.)

CO-CHAIR OKUN:  Absolutely no doubt there.  Let's see.  Ellen?

MEMBER MAKAR:  So as part of this conversation I would be remiss if I didn't mention Blue Button and the fact that the Blue Button Connector is being built in a way to highlight for patients where they can get their data and to what extent.  And that's currently in its first pre-release state and it's something that we want to keep in mind as we think about these measures.

CO-CHAIR OKUN:  So that feels like we've got a couple of label opportunities there, too.  So, okay.  Jen?

MEMBER WOLFF: So I know we're short on time. I'll be really brief. I just wanted to elaborate on the comment about the notion of being able to create some sort of an indicator of an organization's information transparency and to take that a little bit further in thinking about an organization's capacity to make linkages outside of their own system, which I think is really important.

Obviously the denominator might be slightly different, but for people who have disabilities and require long-term care or have social service needs, it's critical that the organization is able to make those referrals adequately. And that would be a phenomenal thing if you had the right denominator and you were able to begin to capture a patient's perspectives about the ability to get the referrals that they need.

CO-CHAIR OKUN: I'm sorry. Dave, go ahead.

MEMBER DEBRONKART: Oh, she was

probably there first.

**MEMBER CONNOR:** I just wanted to add that access to information can also save lives. I'm aware of one situation where a patient went into his medical record and found an abnormal CAT scan, contacted the covering physician who hadn't even looked at any of these test results who told him to go immediately to the emergency room where he then had surgery.

**MEMBER DEBRONKART:** And this is on the subject of dissemination of whatever we do increasingly. So, I had two anecdotes a year-and-a-half ago that I blogged about within a few months where I asked for a copy of what we had just done. One was lab results and the other was an X-ray. And I was told that's not our policy.

So I went on Twitter and said, "All right, I know this is BS. Where's the document?" And within a couple of hours somebody said here's the URL to this HIPAA flyer. And I called back to the practice and I said, okay, I looked this up. I understand this is a federal civil rights violation. Who do I talk to?

Now this is a real guerilla warfare tactic. I didn't beat up on the clerk. I said who do I talk to? She put me on hold. And I know what the conversation was, because she came back in three minutes and said come pick it up.

But now, so the question is what I'm seeing is some people I know who were active in the AIDS/HIV movement said what you guys need to start doing is community organizing. You need to put people in the communities who can give tips like this to other people. So let's think about that for dissemination.

CO-CHAIR OKUN: Well, we certainly have that mechanism in patients like me. There's lots of tips and advice going around in very structured ways, so it's just one other mechanism for that.

MEMBER DEBRONKART: Yes, but the Haywoods don't own the world let. I'm sure they plan to.

CO-CHAIR OKUN: That's not fair.

The other thought I had here was the linkages to the outside the system I think is an important one that we want to be sure that we're -- it's sort of that interoperability capability. And again, I think that's also a label opportunity, too.

So I think one last thing I'd like to mention here and it has to do with patient-generated information sharing, which I don't think we've hit on, but I do think it's a communication issue. I'll share one N-of-1 vignette.

Actually in patients like me we were asked by the American Academy of Neurology to ask our epilepsy patients how well their neurologists were meeting the guidelines for epilepsy care. And we learned on one measure; and it was on surgical referral, that across the board whether you were an epileptologist or you were a primary care practitioner, the referral for a surgical assessment was really woefully low.

And then one of the patients on the site actually had been living with epilepsy for 30 years. Learned about an epileptologist. So the epileptologist scored pretty high compared to everybody else on that one measure. Learned about an epileptologist. Never heard of one before. Had been getting her care pretty much from a general neurologist. Went in. Asked about a surgical referral. Had the assessment done. Was determined to be an excellent candidate. And 30 years into her epilepsy is the first time in her life she's been without seizure.

So, you know, it's that kind of N-of-1 experience that not only may save a life, but might also change a life. And so, it's that information sharing piece that I think somewhere along the way we have to figure out how to be able to share that, whether it's outside the system or inside the system.

We have two more comments and we're going to try to finish in just a few minutes. So, Gene?

MEMBER NELSON: Maureen's comment and your comment have provoked this thought. There's a report to the King's Fund that Al Mulley and others wrote last year, and it's called "Stop the Silent Misdiagnosis." And we have many core concepts that we're looking at for person and family-centered care, and one of them is shared decision making. And that paper speaks to high-stakes shared decision making and it's a matter of fact that people get procedures done or interventions done that are very high-impact that if they were fully informed they wouldn't choose to get.

And that's what Al Mulley was referring to in "Stop the Silent Misdiagnosis" published for the English audience. It does apply here. And so, I think all of these domains are very important and some of them are really high stakes and it's under the water. We don't really recognize it. We don't really see it. And I just wanted to mention that I think important body of work.

CO-CHAIR OKUN: Great. Thanks, Gene.

Jennifer and Maureen, do you have final comments? Your cards are up.

(No audible response.)

CO-CHAIR OKUN: No, no. No problem.

Okay. I think actually we did a really good job on time management here. Actually it does seem to me though that a lot of conversation on these two domains really have label opportunity, so it's something I think that you could definitely take under consideration there.

So, all right. We're ready to move on to Group 3. And we have a half hour until lunch and so we may get just through one of that.  So maybe No. 5, Bruce, if you want to start with that and we'll go from there?

MEMBER LEFF:  Nah, we're going to go through both of them, Sally.

(Laughter.)

MEMBER LEFF:  All right.  So our group had a lot of very good discussion.  We didn't drill down into details.  We were a bit in the clouds and we got below the clouds a bit.  And I will rely on my group mates to slap me across the head if I get things wrong.

So we're on Core Concept 5.  My family care partners include those I choose and their role is supported by other care partners.  So at a conceptual level we had a lot of trouble with this as a single combined core concept.  We struggled with that a lot and we ultimately decided to split rather than lump.  So we split them into two.

The first was the notion of including those that I choose.  Conceptually we had some extended discussion. Does the word "include" include only those that I choose, or do we go beyond the -- you know, the word "only" is not in there. And so, that's something clinically I can tell you as a geriatrician I struggle with a lot. I'm seeing mom or dad and a daughter calls or a son calls and it's ambiguous whether the patient might want me to be talking with them or not, or they say don't talk with them. And I think it really is in my interest. You know, so there are all sorts of things about -- so should the word "only" be in there as a concept issue?

Thinking about the second construct, this notion of supporting family care partners. We had a lot of discussion about this construct of what a family care partner was versus what care partners were and how broad that circle gets. And, you know, we could think of care partners in the care of say homebound elderly or disabled elderly to go way beyond what we would think of in the usual healthcare system.  So a minute clinic may be part of that system.  Meals on Wheels may be part of that system.  A geriatric case manager who's nowhere in the health system may be part of that person's system.  So we talked about all those things quite a bit.

When it came down to putting some stickers on the sheet and playing with the dots, we tended to focus more on that second construct of supporting family care partners. We thought there was a lot of useful information on the grid that you all provided, but one process construct we adopted was the notion of assessing the family care partner. In terms of a structural construct we thought a lot about the notion of how practice -- not a medical practice, but practice broadly writ -- the infrastructure could be thought of in terms of a structural construct.

So the notion of, you know, could there be structural IT things built into a system to help in terms of this notion of supporting family care givers? Could the notion of structure, the relationship that an entity has with appropriate services to support the family care partners -- and that could be practice and non-practice-based. So just trying to think about it in a very broad ecosystem of care.

In terms of outcomes, we liked what was on the sheet, the notion of assessment of patient and caregiver experience with regard to support of family care partners, by other care partners, gets a little wordy and awkward, but that's where we ended up on Concept 5. And I'll ask my colleagues if I've left any significant portion of our discussion on the cutting room floor that I should not have. Anyone?

(No audible response.)

CO-CHAIR OKUN: So do we want to open up some discussion on this one? Everyone feels like --

(No audible response.)

CO-CHAIR OKUN: Wow. Either we're getting on overload or -- Kevin?

MEMBER LARSEN: So one of the things that seems to me to be a theme throughout our whole time is we're asking actually the patients here to do a lot of the measurement. And I'm curious if you guys thought about ways to do measurement that weren't just survey of the patient or caregiver, or especially just the patient. I mean, was there some caregiver assessment here or is there some way that we also do -- that the burden of measurement falls not to the patient in this case?

MEMBER LEFF: I don't know if we discussed that explicitly. Someone can remind me if that was --

MEMBER RADWIN: Yes, I mean, we talked about if you have a document -- if the clinician document is an assessment of the care partner or the family caregiver. That's not a burden on the caregiver to respond. You have a document assessment. It's a process measure I'd assume. And I supposed you'd have standards of completeness for the domains that you assessed. Does that answer your question?

MEMBER LARSEN: Yes, I mean, I -- so remember my job is to try to figure out from the bread crumbs that we do in the EHR what can I actually make of measurement that has no burden on all the people involved. It sort of necessarily captures data that's already there. And there are actually two reasons for that. One is because it's less burden and we ideally don't want people investing all their money in measurement. We want them investing their money in the work and the improvement.

But actually the second one is almost more interesting. It's that the system is much less likely to be gained if we're using data that's collected for the primary purpose of really good care delivery. And we can secondarily measure that that really good care delivery happened. So when we introduce measurement just for the sake of measurement, we actually introduce all sorts of reasons for bias and confounding just because what we're doing is measuring for the sake of measuring.

MEMBER WOLFF: So I just wanted to just take a step back and elaborate very, very briefly on this notion of caregiver assessment. And this is really a different -- this is an orientation towards -- I'll just read a quick definition. There's been a lot of work in this area. There's been consensus around what caregiver assessment means. There are many, many measures of caregiver assessment that now exist. I'll just read you a quick definition.

"Caregiver assessment is a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths and resources of the family caregiver as well as the ability of the caregiver to contribute to the needs of the care recipient."

So the application of caregiver assessments has varied widely.  It's been largely deployed in research studies to tailor interventions or delivered through social service agencies to caregivers who self-identify has needing services and largely has been focused on outcomes of the caregiver. And there's a large body of evidence showing that caregiver assessment, when paired with service referrals to meet identified needs, does contribute to better outcomes of the caregiver.

So to take a step back from that though and to think about caregiver assessment as part of a healthcare or long-term care process, there are some measures that have been developed like the CARE tool that was developed by CMS for transitional care for patients as they move from setting to setting where there is an assessment of the patient's perceived network of people who are caring for them, but the caregiver is not specifically talked to. So it's the patient's perceptions of the caregiver's ability to provide needed care on discharge for the hospital, as an example.

So the challenge here is that the idea of caregiver assessment and pairing assessment with services to meet the needs of the caregiver is focusing on the caregiver. In the health system, the orientation is predominantly to the patient. However, when the patient is reliant on the caregiver, it's reasonable to believe that the caregiver's ability to provide care that's expected of them may impact the patient as well.

So there is this idea of potentially collecting information, not for the purposes of surveying alone, but to actually target services and appropriate referrals. There is not an existing body of evidence of what questions you would field.

Some caregiver assessments are two or three hours and are very involved. I think that's not practical for the purposes of a healthcare delivery setting, but clearly there is the potential of using some screening questions to identify when a caregiver is not prepared to provide care for the patient or is at risk of burnout and/or bad outcomes for themself where there could then be further follow-up and deeper questioning about the experience and the circumstances and then provision of referrals.

So I wanted to talk a little bit about caregiver assessment because it's not typically part of this kind of a discussion. I also wanted to separate that from what our group discussed, which was actually assessing caregivers' perceptions of the system and some notion of a caregiver CAHPS, which is largely missing now except within the context of nursing home care. So those are two separate pieces. I just wanted to sort of pull them apart.

CO-CHAIR OKUN: That was an excellent distinction. Thank you very much.

Annie?

MEMBER WALLING: This is a little separate idea, but I think interventions that lead to better caregiver outcomes, too, might be processes that we could look at. And I'm thinking about the New England Journal RCT about family meetings in the ICU. And I know this is one specific intervention, but that's a measurable thing that led to lower rates of -- these are screening tools but below the threshold of PTSD, anxiety and depression for patients who had a structured family meeting and bereavement support.

CO-CHAIR OKUN: I think the other thing this lends itself to is really giving -- it speaks to the efficiency and utilization of my time. So as a caregiver allow me to do some assessment of my abilities in the time frame that's useful for me and not necessarily on your time frame.  So being able to do that on my own time or on the computer or on different modalities would be important.

**MEMBER LARSEN:**  Yes, I mean really am supportive of this.  I'm trying to sort of think through where are the multiple-tude of opportunities for this, you know?  So, you know, is there an opportunity that there is a routine process to engage with caregivers to do this kind of work?  You know, are caregivers included routinely in my discussions around my care and decision making?  So I think there are some maybe even more proximal things that might be needed and part of this path.

The experience I have building measures for this actually comes in pediatrics.  We're working to build a measure of screening mothers at children's postnatal visits for perinatal depression symptoms.  So, the caregiver is the mother, but the visit is the baby's.  And I think everyone can understand why perinatal depression treatment is actually the best thing for the baby, not just for the mother.  So it makes really sort of logical sense there, but I'll tell you that the operational and patient privacy hurdles are really high, which doesn't mean we shouldn't forge ahead, but it's forge ahead and say that it's really important.

CO-CHAIR OKUN:  You know it also seems to me that there may be an opportunity where it seems appropriate or where in some of these other concepts it seems to fit that when my care is coordinated with my family care partner that I may be assessed as to what my preferences are and my goals of care and the things that I have.  And then my caregiver is as well.  And that we actually determine is there some congruence or incongruence between the two that could actually then improve the ability to communicate and integrate and stuff?

So it feels like there's an

opportunity there that may yet need to be fleshed out. Lori just can't wait to get on this one. But I think it's just really an incredible opportunity.

MEMBER FRANK: Yes, really excited about this one. So it's a unit of analysis issue and the dementia researcher in me just leaped out.

(Laughter.)

MEMBER FRANK: So the uncoordinated one.

(Laughter.)

MEMBER FRANK: So, you know, the idea is is person-centered care and family-centered care really about elevating that unit of analysis beyond the patient to include the care environment for the individual? So that's health environment very broadly defined. It's housing, it's transportation, et cetera. But, you know, more importantly and a little closer in then is who really should be involved and could usefully be involved and then what are the measures around that?

CO-CHAIR OKUN: I think the other thing are the implications when we're not doing a good job at assessing what the needs are for the family caregivers and really then leaving them, you know, ill-prepared to deal with what they need to.

I mentioned this at dinner last evening and it's just an interesting way that I tend to view the world sometimes when it comes to family caregivers and the contribution, the economic contribution and all other ways that they contribute to this society. And if you've never seen the movie A Day Without a Mexican, it's sort of a cultish movie that's got a little tongue-in-cheek, but it's quite serious. And that's: what would California be like if the Mexican community didn't show up to work?

And so I think it would be, you know, a similar movie would be what would our health system look like if family caregivers just didn't show up one day? And we would be hugely burdened, you know, to Joyce's point. So quantifying that in some way and then understanding and being sensitive to their needs in that assessment would be a huge part of patient and family care, I think.

MEMBER MAKAR: So I just wanted to mention, to add on to your point there that the Work Force Group -- I did a presentation for them on Carers. Right. The U.K. has a big movement right now on Carers. And one of the things that we talked about was in the training talking to personal care assistants, aides, nurses, everyone about how to interact with caregivers and training around that. And also thinking about training for caregivers. It's on the radar.

MEMBER LEFF: So No. 6, my care partners provide information in a format I prefer to answer my questions, help me understand my choices about my health, health problem, treatment care, costs, or providers and increase my confidence in capacity to care for myself to the extent that I am able.

So we had some conceptual issues that would influence measurement in terms of providing measures relative to what health issue and in what time frame, just thinking about the complexity of health issues if you're thinking about a measurement.  Is it around a specific health event, an episode of illness, something that pops up one day and might be gone the next?  So that's not a trivial issue.

In terms of some structure processor outcomes that should be measured, we were thinking here about some outcomes, and I think this was from Lori.  She came up with, "Did you get the information: you needed to take care of yourself, to anticipate what might happen to you?  Did you leave your encounter with questions unanswered?"  So those would be some survey-type measures around that construct.

In terms of a structure we were thinking about the ability of the system, again broadly writ, to deliver information in a flexible manner to patients and caregivers. So flexibility in terms of when it's delivered, the mode in which it's delivered, whether that's on paper or electronically or in person, appropriate to literacy level of the patient, appropriate the language needs of the patient, appropriate to the readiness of the patient to learn, and appropriate to any sensory impairments that the patient may have.

Anything the group would like to add to our --

CO-CHAIR OKUN: Anything, others?

(No audible response.)

CO-CHAIR OKUN: So it does feel like there's opportunities for us to pull from even some of the other points where we talked about things of information gathering and sharing that sort of thing for this one as well.

Troy?

MEMBER FIESINGER: Yes, basically I would look at merging this as much as possible with 8, because it's almost the exact same discussions we had outside of the inter-caregiver communication.

CO-CHAIR OKUN: So there's one thing on this one though that I think I would like to call out, and that is my ability to increase my confidence and capacity to care for myself. That feels different to me, yes. So it almost feels like maybe the information component of this goes to 8. But the self-care capacity or my ability to care for myself to the extent I am able, does that feel separate? Yes.

MEMBER RADWIN: When I was going through it, it felt more like an outcome, you know, and the burden in this sector, this concept is the burdens around -- the emphasis on information leading to self-efficacy sometimes -- you know, it's every educator's burden. If you just taught them the right way, they'd be able to do this. And that's not the only thing that leads to competence or capability in self-care. And, Sally, when you said it felt different, that's the reason it felt different to me. It's an outcome that can be influenced by information sharing, but it's necessary, but it's certainly not sufficient. And so I'm wondering if it even has a place there.

CO-CHAIR OKUN: Well, if we pull out some part of into 8, is there some way where we still attend to the ability of -- or is it too much of an outcome to be a core concept, the self-care capacity?

Yes, Karen?

MS. PACE: I was just going to say I don't think that necessarily makes it something that shouldn't be a core concept. I mean, a lot of the core concepts are in one sense outcomes because they're the experience.

So the experience of feeling confident to care for yourself seems to be an okay -- but --

MEMBER RADWIN: Yes, I mean, honestly I think you could take any concept and maneuver it such that it becomes an experience concept. You know, just the experience of being self-efficacious, the experience of having a high vitamin B level. I mean, you can turn a lot of things into an experience. You know, if it's a core concept of patient-centered care or an antecedent or consequence to it, I think we have to be pretty distinctive, otherwise our measurement is going to be pretty clouded.

CO-CHAIR OKUN: So there's one thing though that is striking me here and that is what you mentioned before, that it's not simply information that we provide that increases someone's ability to have some self-care capacity, right? So it feels like we've confounded the ability and capacity and the confidence to be able to care for self to the degree I'm able with the delivery of information. Do we all agree that we need to separate those two?

All right. So the first part of this concept seems to fit with No. 8, but the second part of this concept seems to stand on its own absent of it being dependent on information alone, that the idea of my care partners increase my confidence, comfort and capacity to care for myself to the extent I am able. Is that something that we would believe in as important? Because we could lose this altogether. And then I'm just worried that this concept of self-care and self-management, which is something that I think is really important as we move into this, you know, new generation of health delivery. I have to have a role here. So I'm not sure whether we tease it out and make it something on its own and put the first part of this into No. 8 but still retain something about self-care, putting it out there on the --

MEMBER LARSEN: Sally, I've got another point, so if people on this one --

CO-CHAIR OKUN: Gene?

MEMBER NELSON: Yes, this is one that I think for a variety of reasons really should be separated and equal as we move towards value-based payments. For example, Dartmouth-Hitchcock Health System or Kaiser Permanente will be trying to find the ways to get the best outcomes at the lowest cost of production to Dartmouth-Hitchcock or Kaiser Permanente. So self-management that's effective and intelligent becomes really important.

And of course with chronic conditions, especially high-impact and multiple comorbidities, I live with it 24/7/365. And we know from the work of Bandura and Lorig and more recently Wasson that outcomes are better when self-efficacy is high, that satisfaction is higher with my care team when self-efficacy is high, and outcomes and costs are better.

And so as, you know, we think about -- not everyone of course will be capable ever of self-management that's intelligent and consistent and reliable, but shifting the population towards this is very important. So I think, you know, that this is one of those things that -- and Wasson's work shows that this very substantially across practices, primary care practices and it can be improved substantially across primary care practices. So that's some emerging evidence about -- this really counts in the real world.

CO-CHAIR OKUN: And we certainly have evidence of it counting with patients to patients improving each other's ability to increase their capacity and their comfort and their confidence. So I think there is something to be said for not losing this concept.

MEMBER DUBOW: I agree. In

relation to that, I think we also have to assess caregivers' confidence in being able to manage the care of the individual. So I think those are sort of parts of the same issue.

Also I remember on the initial list someplace there was some mention of activation, and I wonder whether we ought to think about patient activation in this context. But I say that with some reservation because, you know, we know that a higher activation levels leads to better outcomes and we know it can be changed. I just don't know whether activation as a public report is useful or whether that's simply a tool that providers should be using. I'm still thinking about that. But so I'm not sure that it's useful for both QI and public reporting and accountability, but I do think that those are concepts that are related that we ought to think about in this context.

MS. PACE: Where you saw it was on the sample framework as a potential outcome measure. But just so you know, I've heard that the patient activation measure is going to be brought to NQF for consideration.

CO-CHAIR OKUN: I just read something about the activation measure being used more broadly, and one of the things that I read; and it just astonished me, and I actually copied and pasted it quickly -- and it was that clinicians were not -- many places where it's being used were not actually sharing the scores with patients. And it was a very paternalistic reason, because they weren't sure they would be able to make sense of what that was about.

So now, it was in the lay press. I would certainly want to go further and explore it. But if that were the case, I certainly wouldn't want it as a national measure if we're not going to then give the patients the ability to do something with it or provide interventions that will help them move up along the activation --

MEMBER FIESINGER: So I agree it's fundamental. It's essentially all the successful chronic disease patients are self-activated and take care of themselves. Your heartburn won't get better unless you quit smoking and drinking whether or not you take Prilosec.

So as I think about this, a couple thoughts: One, if there's already going to be a patient activation measure, do we need something on this? It needs to be somewhere. Does it need to be here?

Two, how are you going to measure it? I would want a measurement that stimulates care groups, caregivers to assess it, teach people about it, try to improve it, but I would think carefully, do we want a process versus outcome, thinking of the burden on basically as a physician a physician's one more thing.

MEMBER FRANK: So I think that 6(b), if that's what this is, should come out separately. I think it's about supporting an individual as an agent in their own care. You could break it down and make it more measurable by focusing instead on supporting the patient as a decision maker in their decision making about their own care.

And then so, you know, that leads me to; just want to clarify, when we talk about principles of person and family-centered care versus core concepts, if we're all thinking about the same thing. So, you know, arguably this is a principle then and could go with honesty and transparency and compassion, respect and dignity, but I would advocate for keeping it separate, combining it with 4.

MS. PACE: Well, I think the original intent was it wasn't just about decisions. It was about actually being able to follow through on whatever the care --

CO-CHAIR OKUN: Yes, and at times where decisions weren't necessarily needed to be made. Decisions may have already been made collaboratively, but now I'm going out and I'm exercising what I need to do to be confident in my ability to do that. But I can see how you see them sort of linked, but --

MEMBER FRANK: They're linked or you could bring it up from the decision making and make it decision making and agency about care.

MEMBER LEFF: Yes, I love that term, getting the word "agency" in there as a very active flavor to it. I really like that.

MS. PACE: Will patients relate to that term?

MEMBER LEFF: I don't know. I doubt it, but I like it for us, yes. And all the ethicists will love it.

But coming back to a lot of the points you've been making about -- I think this notion of agency does allow for a virtuous circle where people will become more involved, and it should. You know, this feels like a higher-level thing that if it could be influenced can really percolate through a lot of the constructs that we've been developing.

MEMBER CONNOR: As part of this group, when we were trying to come up with metrics, I kept thinking, as we were reflecting on them, haven't we heard these before? And actually I think it would be worthwhile, picking up on Jennifer's point, to look at those questions because I do think some of them have relevance and may be very useful for this work.

MEMBER RADWIN: Two concepts again from some qualitative literature: One of the things that patient-centered care provides by sharing knowledge of a trajectory of a disease or of other patients in circumstances like your own. I mean, clinicians do that, too. Patients do it for each other, but you know, we hear, you know, if you're going to get this kind of chemo, the nurse will tell the patient you're going to be down and out for two days. You're going to feel like you're something and then we're going to whack you again. You know, that trajectory of an issue helps a person develop insider expertise. That's Jerry Lam's finding.

And so that helps a patient be prepared to be activated to care for themselves. And, you know, I just think about what is actually the process and the delivery of patient-centered care and what do we get when we do it. And whether the outcome of self-efficacy or self-care ends up as part of another core concept or not, it's distinctive from the process of delivering patient-centered care. And that's the point I wanted to make, yes.

MEMBER LARSEN: So I want to move to the information one, and I want to be sure that we don't under just some big rubric lose the good work we've done at sort of specific sub-areas of information. And so that as I think about how they've kind of played themselves out, the one we talked about most predominantly in the No. 8 was my information is available to me and my family.  So that's about my own personal information that has been collected, labs, whatever it is.

Then my information is available to all my care providers.  So that's specifically talking -- and we could take out "care" -- to all the providers that I think are important.  So that's not now my family unit.  It is the others in this network that are part of the system.

And then third one, which is I think is what's called out here, is I have access to information to make decisions on care providers and costs.  So that's really not my data.  That is aggregated data in some way and it's somehow predictive data or it's future-looking information.  And so that's a different kind of information access.

And one thing I might point out to you, yes, it's hard, but it's being done.  So if you want, you can go to myHealthcare Cost

Estimator. And UnitedHealthcare Corporation has put out all of their analytics that they've done for years around health plans and they profile procedures and clinicians based on the health plans that you have through UHC and they can tell you what it would cost you to go and get your surgery at any of a number of places in your market. So things exist.

And the question is how do we be sure that that kind of information is in the hands of people as they're out making decisions about where they're going to seek care.

CO-CHAIR OKUN: That's a very important point and I think that more and more when we put that data into the hands of people outside of the system, they're actually very creatively learning how to deliver it effectively to people. Go ahead.

MEMBER DUBOW: I don't know myHealthcare Cost Estimator, but I think we need to think about not the one-off, sending people off to these things when there are tools that factor all of the pieces of information in one tool. Krukoff has done this. So that when you are making a selection of a plan, you can sort by the factors that you are most interested in. It's absolutely patient-centered. Some federal employees have access to this. I don't know which agencies, but there are a few of them that use it. So you can sort by quality, by physician, by cost. There are actuarial estimates about what your out-of-pocket costs are going to look like based on utilization experience.

So I think that the single item or the single-type tools are not patient-centered because you have to go searching for them. So that we need to think more comprehensively about marshalling all of that information together so that it's easy to use. And these do exist, to your point.

CO-CHAIR OKUN: So that feels a bit like a long-term objective of gathering the data from -- in a short-term way looking at all the potential sources and then long-term having one place where someone could go. And as a provider or care partner part of my job is to be sure that my patients are able to get access to that information?

MEMBER DUBOW: Well, to provide access to it. I mean, you know, and again it depends on the unit of analysis. But a health plan or a purchaser or a payer could provider this information out, or in exchange. There are lots of levels of analysis and lots of entities that could be providing it. The individual provider? No, I don't think so. But I think depending on the unit of analysis for measurement, I think we could have this expectation. I think it's reasonable.

MEMBER LARSEN: And I think this is where the nutrition label idea could really be of use. So there's going to be a proliferation of tools, and there should be. And there should be some variance in what different components are.  But to really have a consistent experience by which a patient could expect to interact with that information across lots of different kinds of places, application sites, so that they know calories are here, serving size is eight ounces, I'll get the saturated facts pulled out separately. That's my out-of-pocket cost pulled out separate.  There's some expectation for a standardized format for how the information is pulled together, which allows for diversity of programs, plans, reasons, et cetera.

And sometimes it might not all be filled out, you know, and it's going to take us a while until we get there, but it should be thought of as a whole.  And we don't have to create the tool.  We don't have to create the software.  But if we create the expectation, the way the label might look, that lets everybody sort of move themselves to that spot.

CO-CHAIR OKUN:  I don't see any

cards up and we have gotten through all of our work. So we are ready for lunch. And I'll let Karen take it from here.

MS. PACE: Yes, definitely we'll have lunch. And, you know, we'll take at least a half hour. And then what we'll do after lunch is just kind of try to do some summative things, kind of check in with everybody, your thoughts about short-term/long-term, anything that maybe was missed.

But definitely good work, good ideas and you deserve a lunch break. We were contemplating working through lunch and you actually get to have lunch. So let's take a half hour for lunch, reconvene at 1:15 or 1:20. We'll summarize and we'll see where we're at. Thank you.

(Whereupon, the above-entitled matter went off the record at 12:41 p.m. and resumed at 1:15 p.m.)

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

1:18 p.m.

MS. PACE: Okay. Thank you all for getting back. I know our numbers are dwindling.

Operator, would you check to see if there's anyone that wants to make a comment before we get on to our last discussion?

OPERATOR: Okay. At this time if you'd like to make a comment, please press star then the number one on your telephone keypad.

(No audible response.)

MS. PACE: Okay.

OPERATOR: At this time there are no comments.

MS. PACE: All right. So first of all we want to acknowledge all of the good work and thinking that you all have done over yesterday and today. And we thought we would just use this last bit of time -- and, you know, if we end early, that's fine. Good for everyone. But we'd like to just go around the room and ask each of you to maybe weigh in or make some observations or comments about short-term versus long-term, things that you think are kind of ready to move on now versus things that are going to be on a longer trajectory.

And to get us started off, I'll just -- Gene Nelson had to leave early, so he left me with three things that I will share with the rest of you. And then, you know, we'll go around room and see what your thoughts are. And then we'll just remind you about kind of next steps and we'll adjourn.

But Gene had actually three recommendations, and these probably -- I think this first one is actually more of a longer-term. He referred to it as measure cascades. And his idea, which he already mentioned, is the Person-Centered Care 10 like the PROMIS-10. So his idea is, you know, really to work with a group like PROMIS and actually develop that kind of instrument where all of the concepts can be measured and drilled down into sub-concepts. So that was one of his recommendations.

His second one was that he thought that the priority for measurement should be on the patient-reported information over and above structure and process.

And his third recommendation was to try to get a group together that combines PROMIS and CAHPS people. And he mentioned that there are some people that work in both. Specifically he mentioned Ron Hays has worked with PROMIS and with CAHPS. And to really get them to look at short-term, what kinds of measures are good enough versus longer-term, developing better measures. And, you know, perhaps the CAHPS people might learn from some of the methods of the PROMIS that they've developed over the past 10 years in terms of their methodology and being able to drill down, or the computer-adaptive testing, et cetera.

So those are Gene's recommendations. And I guess, Annie, do you mind starting? So the idea is if you have, you know, again anything that you think is short-term versus longer-term out of what we've discussed, or if it's something that has newly occurred to you. But, thank you.

MEMBER WALLING: All right. I was thinking one approach to short-term/long-term could be need, so populations of patients with higher level of need. So for example, some of the vignettes that we heard about the nine-year-old with terrible asthma who -- he obviously really needed a patient-centered plan in order, or patients with multi-comorbidity, or advanced dementia and serious illness as well are all patients where there's more dire need to provide patient-centered care.

And just a place that we can look for data, you know, I can just say that palliative care has sort of begun, I think, as sort of a specialty within medicine, to try to satisfy a lot of the need for patient-centered care. When people ask me, you know, so what is palliative care, I always just say, it's really good care. We happen to have to focus it on patients with higher need, because those are the patients -- because we have limited resources. But I think everyone would benefit from good communication, good symptom management, coordinated care and multidisciplinary teams. And it's really what everybody's been saying.

So there's actually a growing and rich literature in palliative care, so there's a lot of data there that I think that we could pull on. And then, of course, longer-term I think all of these things would be great to see for everyone.

MS. PACE: Thank you.

MEMBER NYMAN: I like Gene's recommendation, that PROMIS-10 or Person-

Centered 10, yes. Like I was saying before, as far as being respectful of its time and trying to keep your question sets short, that group seems to be one that has a prime principle. So I think that resonates well.

And for short-term, you know, I think I've already called out a lot of measures that are already out there that aren't actually categorized or grouped as, you know, patient-centered care outcomes or whatever, and maybe just highlighting what's already being done within that space would be helpful.

MS. PACE: Maureen?

MEMBER CONNOR: I would suggest reconsidering the core concepts in light of the recommendations that were made today, perhaps bundling some of them and reconfiguring what makes the most sense. I also would recommend that we do look at what's out there, such as picker questions, survey questions, just to ensure that we are not missing something that's available.

And I think that I do agree that the person-centered care should come first over structure and process as a short-term activity, but I would consider looking at the system in the long term.

MS. PACE:  Michael?

MEMBER LEPORE:  There's really two points that I want to push forward.  One builds on one of Gene's recommendations, and with regard to the various CAHPS surveys, I think there could be a great opportunity for creating composite measures from select items that focus on things like compassion, respect. So it may not be single items, but composite measures.  And the Leap Frog Group did a nice job with that on creating a safety measure.

And so they've published exactly what they did, the sort of group they brought together to do that, and it could be a useful model if we do take that route of composite measure development.

And I also want to encourage us all to continue to pull back the lens on systems beyond healthcare provider systems, but to take into account housing, transportation, all of these human factors and I think, maybe remembering an example that I've encountered in Brazil where their push for patient-centered care doesn't use that term.  It's humanizing healthcare.  And maybe just remembering that humanization of care is potentially another word for what we're pushing for.

MEMBER WOLFF:  So I have three points that all sort of touch on the non-standard patient.  I think, you know, we already have a number of measures that are in place, and I think it's great to build on CAHPS and PROMIS.  I guess I would love to see a lot of focused work outside of the easy, healthy population, populations that may not be able to answer CAHPS by themselves.  For example, how do we think about quality of care for the patients that Bruce sees in clinic, that are really challenging, and really thinking about what does quality care mean for them?

Secondly, to build on Michael's point, I think it's really important, is illuminating the broader experience, beyond a single healthcare setting, to really focus on the patients' experience as they encounter care over time and across settings, recognizing that the vast majority of care happens in the home and outside of these brief, episodic interactions with the health system.

And then the third piece, which is really sort of central to what I think about, is the ability to tease out the patient and family experience. And there really are no measures that are currently in use that get at the family experience of care.

And so, in the discussions over the last couple of days it seemed as if there was some support for two pieces that address this: Number one, specifically eliciting patients' preferences for family involvement and having that being supported by their care partners.  And then secondly, some level of system responsibility for eliciting and addressing the needs of family caregivers when the care plan is reliant on that family care partner.

MEMBER LEFF:  Yes, so a few stray comments.  Number one, I've been struggling a whole lot with the notion when we go to do these measures about the notion of attribution.  I mean, that is a real conundrum, because you want something that's going to span settings.  You want measures that will actually be, you know, as Joyce was saying, accountable measures that actually improve quality.  To do that they have to be attributed to someone.  They have to be attributed to someone or some entity that is specific.

So I like Gene's notion, but I worry that we're going to end up with, you know, the PC-10 for hospital, and the PC-10 for the clinic, and the PC-10 for the house call visit, you know, just like the whole other suite of 10 questions that need to be -- you know, that we create full employment act for PROMIS, which, you know, for them that would be nice.

So thinking about attribution, I think, is really a key set of thought experiments to do here, because if you can't attribute, you might as well pack up the tent and go home, because you won't change anything.

The other thing I wanted to circle back was this notion of the food label. So, you know, one thing about a food label is that, you know, a candy bar, you can measure calories, and that number of calories in the candy bar is going to be the same in Washington as it is in San Diego, as it is in

Minnesota. And so thinking about a food label in this context, would you just want to report averages, right? If I'm a consumer, do I just want to see what the average performance is, or do I want to know what the extremes of performance were, relative to a set of people with problems similar to me? So does the food label get risk-adjusted in some way?

The other thought experiment to do -- and I don't have this answer to this, so I'll just pose it. So with a food label, are we suggesting that if we set up a health system, however you want to define a health system, in a place that goes unnamed, and we brought a group of New Yorkers to get care in that system, and then we brought a group of people from South Central LA and we brought a group of, you know, people from Portland, Oregon, are we suggesting that all of them would rate the care experience the same even if their illnesses were the same, just by virtue of culture and all of that? So think about how all of those influences on ratings and sharing of ratings go. I think that's not --

MS. PACE: And I would just like to make one comment. I think the way we've been thinking about it so far is more the things that were identified as structural measures. Like do you have open access to the record? Do you have --

MEMBER LEFF: Okay.

MS. PACE: -- you know, so that it's -- but I think you raise a good point. If you start getting into actual performance scores, then, you know, that does raise another level of complexity.

MEMBER LEFF: That makes me feel a little better about all of that. The other thing, as you move forward, I think it's really important to think about how this gets implemented in a care system that's evolving very rapidly. Very rapidly. So I really believe, if we're just thinking about typical settings of care, we're going to be at a disadvantage 10 years from now, 15 years from now. I mean, I would really think about Walgreens and CVS as a primary care delivery system, and actually potentially as a data gathering system, right? That's a place where you can gather data as well. Really think about practicality of these measures and don't just -- I think if we're going to go for something just because it has face validity, and we don't know that it really will affect outcomes, then we're going to be in trouble.

And I agree with a lot of what Jennifer and Michael and Maureen said about how to think about focusing. I think I would start with the tough stuff first, because if you can't make it work with the tough stuff, it doesn't really matter. You won't be affecting much care. I would not go after the low-hanging fruit. I would use a reverse strategy for that.

MS. PACE: Cille, do you want to

make any comments?  No?

MEMBER KENNEDY:  (Off microphone.) You mean I wasn't yelling loud enough?

(Laughter.)

MEMBER KENNEDY:  Oh, dear.  Okay. I'll pull it close.  And you just wanted me to thank you a second time?

(Laughter.)

MEMBER KENNEDY:  No, the thought, the diversity of perspectives, the amount of expertise in the room is very impressive.  And I also want to make sure to thank NQF staff for facilitating this, and the hard word that they did preparing for it to lay the foundation for everybody to work, and for Kevin, and Ellen, and everybody else at ONC who collaborated with them as well.

MS. PACE:  Ellen?

MEMBER MAKAR:  So I think that this has been a really fun couple of days.  I think this work is really difficult because it's so abstract and it's tough to wrap your head around it.  So that said, if we're having a hard time with it, I think others will as well, so I think it's important to keep that in mind.

Two key points that I would start with: I don't think we can do it without interoperability or coordination of care, transitions of care.  To me those are the biggest things to make everything else happen. So I like the idea of pulling out some existing measures and looking at them as a composite to start and say: this is an indicator that points towards patient and family-centered care.  And we want to move that way, but these things maybe already exist and we can look in that direction with continued work, but if we cannot transfer the information.  And lastly, I totally second that we look at the heavier lift.

MEMBER FRANK:  This is Lori.  Did I miss my turn?

MS. PACE:  No, but why don't you

go ahead so we don't forget you, Lori. Oh, actually, yes, you're exactly right.

MEMBER FRANK: Okay. And I apologize. I was a little late to join. I assume the instructions are to summarize briefly, is that right, our thoughts?

MS. PACE: Summary thoughts, but also thoughts about short-term versus long-term.

MEMBER FRANK: Yes. Okay. So I think short-term, the nutrition label should be thought about as a measure challenge, and what's important to patients. Are there elements of person and family-centered care that we would want to enable patients to be able to make comparisons about, for example, across nutrition labels? So, you know, let's ask the patient. That's always a good place to start.

And then, you know, what I like about the Person-Centered 10 is, to me, it's a way to get at this notion of ensuring that there's some measurement of whether principles of person-centered care are evinced in the care an individual receives.

MS. PACE:  Okay.  Thank you. Troy?

MEMBER FIESINGER:  Okay.  I, too, have really enjoyed this.  It's been great and glad to have lots of non-physicians, because I'm really good at talking to people who are in the same area.  So I appreciate all the divergent points of view, and I always learn a lot, and certainly a lot of ideas to take back, because my practice is right in the middle of trying to do a lot of this stuff. So this is very timely.

This is kind of a mix of short and long-term, but I still am not quite clear on our global concepts versus measures.  And I was trying to make a little spreadsheet to realign things, and we have concepts like respect, choice, dignity and a lot of stuff falls into that.  And maybe you already plan to do this, but I'd like to have some process to kind of realign and reorganize things, as I think you had said, Maureen, in a way that makes a little bit more sense, conceptually, so that I know where a label is going. Because I'm thinking if I'm trying to present the label to the family docs in Texas, what's this? Why? So having the goal in mind, knowing what it's going to say, what it's going to do for them is important.

So certainly, as a patient I want all this stuff. As a provider, I like simplicity. I don't know what the patient care 10s will look like, but I like it. It's been really easy to get our residents, for example, to do PHQ-9s and G87s and Mini-Cogs and Vanderbilts on everybody, because they're quick and they're fast. And that's stuff we have to deal with often without mental health providers to help us. So keeping the measurement burden as small as possible, but having as much impact on the patients as possible. That's always a compromise, but I think that's a goal to shoot for.

And my other provider plea is: please make things actionable. Measure me on something that I can do something about. What drives me crazy about Press Ganey is getting the data back, and I'm not sure what to do. But if it can be, explain things to me differently, or get me a driver so I can get to my appointment, I can fix that. So maybe the question is what's one thing the doctor can do to make you more able to comply with your care plan? And I know I didn't use the right words, but if it's get a driver, get a caregiver, that's something I can take action on.

MS. PACE: Joyce?

MEMBER DUBOW: So I do add my thanks to the staff and to everybody here. I think it was a really good group. I appreciate having had the chance to participate. So I have a list on my napkin here. It's a jumble of thoughts.

So I have a preference for outcomes, as opposed to the process. I'm really worried that we not stifle different ways of doing things to achieve what we want to achieve. So definitely I'm concerned about that.

And I agree about parsimony and measure burden, because we will hear about that when these measures come forth. And I think it's real, and I think we need to think about how we drive resources. So I think we have to be really crisp in what we want.

We may want to think about composites, which leads me to thinking that in the short term we ought to look at the existing opportunities. So we heard from Jennifer about some existing items in CAHPS, cultural competency surveys. There are others where we might want to just borrow, make sure that we can construct something with, you know, that's --

MS. PACE: And I'll just make a note. We've started going through --

MEMBER DUBOW: Right.

MS. PACE: -- to the CAHPS and identifying --

MEMBER DUBOW: Right.

MS. PACE: -- the performance measures and what items --

MEMBER DUBOW: Yes.

MS. PACE: -- go with them, but we're --

MEMBER DUBOW: I know that the NQF staff is doing just that, because that's what you -- you will identify the existing measures. I know that. But I think that's a good place to start.

I think we need to address the continuum of care. I think the unit of analysis, we should not be assuming necessarily that this at the physician level, or at the practice level for that matter. There are many units of analyses. It doesn't have to be a physician office responsible for providing information in a certain way. That could be a health system. It could be a health plan. We have to think about all of the units of analysis that would be relevant. So, I think we shouldn't think silo. I think we should think broadly.

You know, the challenge or the idea of taking the non-standard patient as opposed to the standard one, I think I would take the opposite view. I think we need to use this as an opportunity to educate patients as well as the provider community. I think we need to teach people what they ought to be getting.

I don't think they -- I hate the expression to give them permission, but, you know, that's the trite way of saying that we need to help them understand that they have rights, and should be asserting them within the healthcare system, and reasonable expectation this is the way care should be provided. They need to learn that through the kinds of measures that we put forth. So I think that's useful.

I must say, to contradict myself, that process measures that are good process measures help people have a checklist to know if they got what they should have gotten, but I still think that given the need for parsimony we need to think about that. But we could have processes in a composite that lead up to the good outcome.

Unit of analyses. Take advantage current measures. Caregivers. Did I mention caregivers? I think we cannot ignore the needs that we discussed before, Jennifer described them in her closing remarks, too, abut the need to include -- and I mean the family caregiver, the person who's home who's taking care of that person who may not be able to do it her own. So I think that we have to just consider that part and parcel of where we're going with this.

So I think that's my notes. Preference for outcomes. Okay. Thank you.

MS. PACE: Dave?

MEMBER DEBRONKART: So, let's see. First, let's get started with a baseline on the simple question about how's it working out? While all the other work proceeds I don't see any reason why we can't start piloting, you know, talking to people in grocery stores or whatever to see what kinds of answers we get back, not any formal publishable results, but just start piloting that question. See what else comes up, you know?

Second, it's so important, I think it's going to be so essential -- and we may have to approach this at the level of leadership. You know, maybe we want to have some sort of a CEO-level gathering, or maybe we have small regional meetings where we bring people together, because my understanding is that C Suite people prefer not to have their issues and especially their garbage discussed in public, but say, look, you guys; and I mean guys in an omni-sex way, a lot of these things have been solved.  It is causing harm that your people aren't doing these things.  So we got to do something about that.

The next thing along those lines -- this whole thing -- because healthcare is so complex and so massive and there are so many perverse competing agendas and incentives, sometimes the only way out of something like that is not untangling.  It's just plain, flat-out transformation.  You got to not try to untangle, but just look at what the Heath Brothers called the bright spots.

You know, like in their book Switch, one of the stories was about in post-war Vietnam many, many kids were malnourished and there were many, many knowledgeable people who had expertise in why it is unsolvable. And the only way out of it was they found some isolated areas where the kids were not malnourished, and they figured out what was different there. And I see that here also. The fact that some people have solved these things. Virginia Mason has no more waiting rooms, things like that.

And then finally, I think I mentioned yesterday, but this root question of who defines what quality is. And, you know, at some level I don't see how the NQF can do its work without speaking up on that subject. You know, we have lots of different quality measures, but, as I think I said yesterday, this is the only industry I've ever seen where the definition of quality doesn't start by asking the ultimate user what's important to you?

Well, and I understand why. I mean, how would I know? Here I am. I'm diagnosed by geniuses with of all a sudden, dude, out of nowhere you've got stage 4 kidney cancer. What do we do now? I depend on those geniuses and their expertise. And I'm not dissing that in any way, but it's this giant missing voice. And I have one anecdote on that that is very moving to me. I don't think I mentioned it yesterday. Did I mention the Dutch IVF clinic, in vitro fertilization?

So I've been to visit this place when I was over there. I'd never been in an IVF clinic in the U.S., but these are not happy places. The waiting rooms are filled with people who -- sorry, I'm a new grandfather -- their dream of having a baby is dying. Okay?

And this clinic did an amazing thing. They gave the whole patient community a wiki and six months to talk amongst themselves, and they said, if we could do anything for you -- because it's not always a baby, right? If we could do anything for you, what are the top 10 things you'd like?

And what they came back with, the first two, of course, were to have insurance cover more attempts. But then the number three, the top thing other than a baby, all right, was empathy from their providers. Not just information. Empathy. And the number four thing was separate waiting rooms for families who've conceived, so that the ones who haven't don't have to be confronted with it, you know? And then the fifth thing on the list was the thing that everybody talks about, more convenient appointment times.

But, you know, if we can find out from people what do the ultimate stakeholders really value? So, thank you.

MEMBER EAMES-HUFF: Okay. I'll be fast. So a couple of things, and I think some of these points have been already made. Beside echoing the big thank you to everyone, including staff and people here, it's been a real pleasure being here. And I think it's been a very rich discussion.

I would emphasize trying to keep the core concepts simple, so they're easy to understand. And I know we have a tendency to try and explain all the nuances to different things, and I think that in the end may do us a disservice, that the nuances can be captured in the measurement and what comes out from that.  And we need something that's easily explainable.

I, too, really support the use of outcomes more so than process measures.  I think besides the innovation piece, since we've talked about being individualized to a patient, I worry that process measures may not always capture it, and may not be, in this case, what the patient wants in a particular instance, and having the outcome lets more individualization happen.

And I do think there's a lot already out there, as well as what's in this room.  So culling from that I -- the shorter versus the longer, it's hard to say one or the -- I think there are things that you can -- I see two streams.  There's the working on some things to get some shorter-term things in the pipeline, and also the longer-term, developing that. And that would be it -- and thank you.

MEMBER LARSEN: Well, thank you all so much for giving your time and thoughtfulness and honesty to this. It's really been terrific. This is the kind of work that we were hoping to get, and so it's just been a treat to be part of this.

One kind of meta thing I think we should take from here is maybe some lessons learned from this process. So I for one found the fact that we had a preponderance of people representing patients' point of view really incredible here. I've been many times at this table where what we have are lots and lots of insiders who all speak in insider jargon, and sometimes even entrenched within their own stakeholder position. And I didn't see that here, and it was so fantastic.

And we had really, I think, a lot of breakthroughs in rich and open discussion. So I think that's a sort of larger recommendation this group could make in general, as we move to influence lots of measure prioritization and measure development, is that we need to do it this way.

I think in a related way the vignettes of success I think really helped our conversation.  I think that having a shared grounding in some real stories of success opened us up to who this is for.  It also helped us be more in a possibility thinking place, rather than in a place that was there's no way that we're going to get there.  So I think those are two kind of broader process recommendations about our process and the process you guys crafted and conceived that we could broadcast as part of our findings.

As far as kind of specific outcomes, things that I think would be helpful as we move forward in the next phases of this type of work.  The framework is fantastic, and I think, again, crisp framework that is really easily understood by patients would be terrific.

And then I would love it if we could catalog some measures that already exist into that framework and maybe call out where we see -- we know that they're not ideal, or we think that they may have some opportunity, and the reasons why we put them there. But that gives people this sort of optimism that we could start right now. If I'm Troy's practice, I could just take this and say, okay, I'm just fired up about this and I want to start tomorrow.

Well, hey, look, you're already doing CAHPS, and here's the three CAHPS items that we think probably do this already, so you already have this infrastructure and you can get started tomorrow. I think that would be so powerful as an outcome for this.

And then, from a prioritization standpoint, I think there are two areas of prioritization that would be helpful. One really for us at HHS, which is, what are we ready for measure development? You know, which things are next as we start doing contracts and projects? And again, don't just think about individual physicians.

HHS is big. We're CDC. We're doing community needs assessments. We're doing ACO measurement. We're thinking about a lot of bigger stuff. Sustained innovation models where we measure what's the impact of the new organ, coordinated care networks for regions of coordinated care that span behavioral health and community health.

So we're going to need measures in those places, too, and we're going to be developing measures in those places, too. So don't feel bound to our current constraints, but also say, this is where we think we're ready for that kind of measure development.

But there's another prioritization I think that we need to call, out and this is maybe more to Lori or others, which is: we need research.  Because one thing that I've been learning, as we're trying to fill these measure gaps in measure development constructs is that many times we're actually missing some of the basic research that would really set us up for success to do the right kind of measurements in these areas.  And again, HHS has a lot of the kind of opportunity and resources where we do fund a fair bit of research.

And so in so much we can kind of align a development trajectory that says, you know, here's what we think is ready for a measure development contract, but here's where we think we should do PROMIS-like activity or CAHPS-like, basic activity that we build a research base that then gets us to an opportunity that this can be a fundamental way that we can measure.

Also continued sort of call- out to the group. Help us be creative to reuse the data we already have, because for the reasons that I mentioned, it's less easy to game, and the burden is really not as present.

And I'll maybe end with another vignette. I told some of you this the other day, or yesterday. So as a health system administrator, I knew my system was pretty screwed up about how, as an academic medical center, that we didn't do very good coordination. But about five years ago my dad was diagnosed with cancer. And we live in a small town, and that small town has a number of different medical centers that aren't actually all interconnected. They're different private groups.

So on a Friday afternoon dad went in for a biopsy. They thought it was going to be benign. And by Friday evening the pathologist had read it and called him and said it was cancer. He had an appointment with his primary care doctor on Monday morning, so I went with him. We waited in the waiting room for about two minutes. The doctor was in the room about three minutes later. Had a terrific conversation with my mom and my dad and I. And he said, you know, I think you should see an oncologist. Where would you like to go? And dad said, well, I think I'd like to go here in town. And so his doctor said, sure, let me see what I can do. Left the room.

Ten minutes later he came back and he said you have an appointment at 1:00 this afternoon. And in the meantime you have an appointment for your CAT scan down the street at a private imaging center. And we scheduled some time for you to have lunch in between. So when you're done here, here's your after-visit summary with all of your information and your pathologist's report. Handed it to us.

We drove down. They were waiting for us at the CAT scan place. Dad got his CAT scan right away. And they said, well, if you wait a minute, we'll hand you the image. So we waited another two minutes. And on a CD they handed us the CAT scan image. We went to have lunch.

At 1:00 we went to the oncologist and we waited, again, like a minute or two in the waiting room. The oncologist said, hi, I've talked to your doctor. I've read your CAT scan. I've read your pathology report. Let's talk about your cancer.

And, you know, it was emotional for all of us, of course. And I kept thinking, there's no way my health system could ever do this. This was incredible. But you know, that should be the expectation. That shouldn't be the exceptional time. This should be how healthcare is delivered in the U.S. And he had fantastic care all the way through with lots of terrific doctors.

My dad is a Lutheran pastor, and his doctor would come and pray with him when dad was on hospice in the hospital as he was dying. Really very holistic.

And how are we sure that we're

calling that doctor out as being a fantastic doctor? How can we tell other people that that health system is working when other health systems down the road aren't? And that's our charge, I think, is to really find ways that we can pinpoint and highlight where that great care is happening. So thank for this. This really the right work. It's terrific work and it's much appreciated.

MEMBER DEBRONKART: And how would that be scored on the question do you feel like you were taken care of, right?

MEMBER LARSEN: How did that what? So I'm a big believer in system-ness, and all of us have a role in the system. To his mobile we have to measure all the parts in the mobile, and they have to be in balance. And so, each of us has a role in the system and there's a way to do it. That's what factors do all the time.

MEMBER FRANK: And this is Lori. I just want to add regarding the call for research. I think there's a great opportunity here for some partnerships. PCORI has already funded a lot of projects on patient preferences regarding care and information provision and care partnering. And we're interested in continuing to do so, and always interested in collaborations or partnerships with other groups where we can help jointly advance agendas.

MS. PACE: Laurie?

MEMBER RADWIN: So I really like the idea of a PROMIS-10. I'm a big believer in parsimony and I like the idea of building on what's been done, but as I listened to the story that Kevin told in the beginning about his brother with diabetes, Uma's story, Gene's story about Dartmouth, what's pretty clear is we've had a paradigm shift, and that the most cost-effective, patient-centered care is delivered by teams.

And so when we look to existing measures, I think we have to be highly sensitive to the stems of those measures. Whose behavior is a patient rating, and that is the best place for that patient's care? Is that the player who delivered the most -- I'm not saying it well, but we need to be thinking about who's delivering that care, and getting that accredited to that delivery, whether it be a healthcare coach or office staff, or whomever. And that's my biggest concern about using preexisting measures. We really have to reexamine whose behavior they're focused on, given the team-ness of it all.

And the other thing, when we're looking at existing measures, I think we have to look at measures that didn't make it into CAHPS. There's a lot of research that's already been done out there on good scales and measures of patient-centeredness that we need to, you know, reboot and take a look at those again, because they have already been developed, but they're just not in the database yet. And I want to thank everybody.

I think this has been a wonderful experience. Thank you.

MS. PACE: Okay. Wendy, do you want to make any comment?

MS. PRINS: No, just to say thank you to everyone. It's been a great couple of days, and I think a really, really rich discussion and hopefully it will take us far.

MS. PACE: Okay. And should we check if Lisa's on before you -- Lisa, are you still on the line?

(No audible response.)

MS. PACE: Okay.

CO-CHAIR OKUN: I also want to echo everyone. This has been an incredible couple of days, and it's been great to actually act as your co-chair. I appreciate the privilege and the pleasure.

So I would like to sort of -- a couple of practical things, test our assumptions about definitions and vocabulary, and just be sure that we're feeling confident that we've captured those well, and where we think they're still open for discussion, start thinking about what needs to be more clarified.

I actually love the notion of finding gems that already exist, and maybe giving fresh eyes to things that maybe didn't make it somewhere in the cut, and it's on the editing floor someplace, and maybe because it was at a time when this wasn't a focus of attention, you know, and we're starting to think about transformation.

I also want to think about working hard on the outreach for public comment on this, because I think, you know, we didn't have any comments at all throughout the course of this. And so I think we need to find different ways for NQF to reach the public in a way that we can actually broadcast, and be sure that people are hearing the next phase of this. So, please, certainly we'd be happy to make some -- and I'm sure Dave would be happy to do some tweeting, but I think there needs to be some greater opportunity to reach real people.

And then I think my last point on that would be, I think many of us defaulted to using the word patient throughout the course of the last two days, and yet our charge was persons. So we have to actually be very careful about that. And if we really indeed mean persons, then we need to expand and broaden the reach of what we're doing, and that reaches, I think, some of the other comments there.

I love the image of the mobile, sort of feeling like things need to be in balance, but still sort of circularly in motion, and that sort of thing. So I appreciate that.

And ultimately I think you've heard my talk on this in the past, but I think we absolutely need to start moving this into the public domain so that people can begin to appreciate that they have a role, and they may even have some responsibilities, and we need to get input from them about what that balance is like. Some of that can get reflected in some of the work being done with team-ness, with patients actually being part of the team and being a member of the team. But really bubbling that notion up I think is only going to help us really push this along.

Once we create that notion, we start to create demand from real people saying, well, that's the kind of care I want, of course, you know? So how are you going to show me how to get it? Thank you.

MS. PACE: Okay. This is just to let you know, kind, of next steps, which is not on here. Obviously we have a lot of review and synthesis to do. And, you know, certainly the rich discussion will help us with our co-chairs and advisory group, help revise the core concepts and, you know, I think definitely to lay this out according those. But we will then have a draft report available, first of all, to this Committee to review, and then it will be open for member and public comment.

And June 30th there will be a webinar open to all to present the major findings and collect stakeholder feedback, though I believe that's going to be an all sides sub-task? Oh, okay. Three of the sub-tasks on this performance measure gap. So, but that's certainly at least one opportunity that we can make your constituencies aware of, that it's available for them to participate in and listen to. And then our contract final deliverable is in August.

So thank you, all. We have more work for us and you ahead of us, but this has been great. We really appreciated all of your efforts and attention. It's been a wonderful meeting and thank you very much.

(Whereupon, the above-entitled matter was adjourned at 2:05 p.m.)

# CERTIFICATE

This is to certify that the foregoing transcript

In the matter of: Person-Centered Care and Outcomes Committee Meeting

Before: NQF

Date: 04-08-14

Place: Washington, DC

was duly recorded and accurately transcribed under my direction; further, that said transcript is a true and accurate record of the proceedings.

Neal R Gross

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Court Reporter