

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 LATTI, 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

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

2 8:36 a.m.

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

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

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

20 So, Sally, I'll let you start.

21 CO-CHAIR OKUN: Okay. Well,
22 thanks everyone for coming back and joining us

1 today. I think a lot of good work got done
2 yesterday in the individual groups and I think
3 what we're going to hope for today is that
4 we're going to use much of the morning today
5 to sort of do the recap of the individual
6 groups. So each group will have a chance to
7 present the concept.

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

22 And then the other thing I'd like

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

11 We heard a lot of that yesterday,
12 a lot of people talking about their own
13 personal experiences. And sometimes when we
14 come to these exercises, we start putting our
15 professional hats on and they sort of cloud
16 our ability to really look at it from the
17 personal perspective. So I think we really
18 need to look at it from both. Start thinking
19 about how does this feel for me if I were
20 being measured on this as a clinician or
21 whatever if you're representing a constituency
22 group. But then also how does to feel for me

1 if I'm at the clinical level or if I'm at the
2 point of care? How might this operationalize?
3 How might it look to me? And would it mater
4 to me? And I think those are the very key
5 important questions.

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

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

20 MS. PACE: Okay. So I'm going to
21 go over just -- well, we'll show you here.
22 Okay. So we've totally adjusted our agenda

1 for today. So I'm going to do just a little
2 overview of priorities for filling performance
3 measure gaps so that we can be thinking about
4 that as we're going through the presentations
5 from the groups. And then as Sally said,
6 we'll really spend all the time we need to get
7 through all of the discussion. We will take
8 a break and we'll see if there's any public
9 that want to make comment. We'll have lunch
10 at 12:30. And then we'll reconvene and again
11 see where we're at, take a pulse and see what
12 we need to do. But we can also talk about if
13 there are additional recommendations outside
14 of the specific measure concepts.

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

22 You know, I talked about yesterday

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

16 The other considerations. First
17 and foremost is meaningful to consumers, and
18 hopefully with the measure developers
19 eventually will be built with consumers
20 focused on the entire care experience. And we
21 spent a lot of time yesterday talking about
22 the core concepts and that those really

1 reflect the experience of person and family-
2 centered care. And certainly many of these
3 things should be measured from the person's
4 perspective. And again, I think an
5 overarching question for us to keep in mind is
6 would the information from the measure be
7 meaningful and useful to patients and
8 consumers? So I think if we just kind of keep
9 those in mind, we'll be doing well.

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

20 And the other thing is to just
21 keep in mind -- and I don't know if you talked
22 about it in your small groups, but something

1 that we can continue to think about is whether
2 any of these things lend themselves to the
3 label idea for person and family-centered
4 care.

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

22 So we can start with group 1 and I

1 think that's the handout you have, but group
2 1 was -- Gene Nelson was the leader and Ethan
3 was in that group, Jennifer Eames-Huff and
4 Priti. And is Priti on the line?

5 (No audible response.)

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

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

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

13 (Laughter.)

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

20 MEMBER NELSON: Okay.

21 MS. PACE: And we're going to be
22 flexible on time, so I guess we'll kind of try

1 to keep track, but we've got, you know,
2 basically the whole day to get -- I shouldn't
3 say -- not the whole day, but until lunch time
4 to get through all the groups.

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

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

11 (Laughter.)

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

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

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

22 The second is care centered on my

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

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

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

9 Ethan?

10 MEMBER BASCH: I don't have much
11 to add. Just going through, we debated about
12 the first one, seeing the patient as a whole
13 person because we felt this is a very
14 important concept but is a challenging thing
15 to measure. And we spoke a little bit about
16 whether this would be a patient-reported
17 measure. We talked about the concept of a
18 whole person and whether that's actually
19 measurable. And we thought about the core
20 components of being seen as a whole person and
21 felt that potentially a measure developer
22 could break that down into several discreet

1 components for measurement, but we felt that
2 this really was ideally suited for a patient-
3 reported assessment probably with multiple
4 assessments.

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

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

22 And then finally the staff

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

10 Was that colorful enough, Gene?

11 MEMBER NELSON: Beautiful.

12 MEMBER BASCH: All right. Thank
13 you.

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

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

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

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

22 CO-CHAIR OKUN: So open it for

1 some discussion. Kevin?

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

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

20 MEMBER LARSEN: And then a
21 clarifying question about your PRO. Is this
22 kind of a process measure or a structure and

1 process measure that says PROs are routinely
2 available to be used in a clinic and PROs are
3 routinely used, or is it something that you're
4 actually -- is it some composite of a lot of
5 different PRO outcomes?

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

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

18 MEMBER LARSEN: Yes, I mean, just
19 to expand on this, this could be both having
20 an EHR with the ability to collect PROs
21 through a portal and then secondarily the
22 proportion of patients who actively report and

1 then maybe even the proportion of patients for
2 whom a provider signs off on the electronic
3 report in the EHR or something along those
4 lines.

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

14 So I think if we don't have some
15 sort of time frame that says there's something
16 that occurs at the institutional or the
17 clinical level that suggests they're ready for
18 me when I get there so that they know me as a
19 whole person to the degree that they can, and
20 then I can best measure that later. So that's
21 almost like a short and a longer-term kind of
22 perspective that maybe we can measure it in

1 the post-experience. But then we need to back
2 into how do we improve the pre-experience.

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

19 MEMBER NELSON: So I understand
20 very well the point you're making, Joyce, and
21 one image is we have a measure concept that,
22 let's say, the people around this table and

1 others might understand what we mean to get at
2 and then to turn that into a measure that the
3 regular individual would answer and answer in
4 line with this concept that has been laid out.
5 That's where the qualitative work happens.
6 That's where the cognitive interviews happen.
7 We mean to measure X in this population.
8 We're using these funny descriptive words in
9 our concept, but what words would you actually
10 use that would make sense to the individual?

11 MEMBER DUBOW: And all I'm
12 suggesting is that this may be a place where
13 the process measures might guide both
14 clinician and patient understanding of what we
15 mean, because it's multifactorial, obviously.
16 But, you know, the annoyance of people having
17 to repeat medical histories a hundred times
18 even if it's in the record, but, you know, the
19 failure to refer to it, or the -- you know, as
20 Sally points out, the lack of familiarity.
21 You know, what are you here for? You know,
22 the reading-the-record-as-you're-standing-

1 there kind of thing. It just seems to me that
2 we need to -- you know, sometimes a process
3 helps a little bit. But again, I understand
4 the testing part.

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

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

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

17 MEMBER BASCH: I was going to say
18 I was a little bit interested in this last
19 one, the staff training. And, you know,
20 potentially one could embed in that sort of
21 staff training in the tenets of patient-
22 centered care delivery and one could actually

1 specify what those tenets are. And one of
2 those could actually be, you know, not reading
3 the chart for the first time in the presence
4 of the patient and so on and give some
5 guidance to what staff should be thinking
6 about.

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

21 Now, those are both more expensive
22 than the kind of easy Web-based training we

1 do, but I would call out something in here
2 that we would want it to be -- know that this
3 is effective training that has been
4 demonstrated to actually move the needle.

5 CO-CHAIR OKUN: Yes, Troy?

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

14 (Laughter.)

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

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

14 So if you're getting at whole
15 person, one way to approach that might be
16 vignettes. Because what we've been doing is
17 we have examples of each level. Is that
18 resident like X? So did they not ask you
19 about your information ahead of time? Did
20 they not have it? Or they had it. They knew
21 me. They knew my sister's name. They knew
22 that my dog is brown. And I'm being a little

1 facetious, but you can have examples in your
2 questionnaire to the patient to get a better
3 feel for it and then at least quantitate it
4 somewhat. Because it's muddy, but it's really
5 important.

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

18 So I guess I'm going to keep
19 pushing on this. If you were a patient or
20 someone looking at quality performance
21 measures and you had to measure what
22 percentage of the patients had a comprehensive

1 history and physical in their chart, would
2 that give you confidence that that was an
3 indicator of person and family-centered care?

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

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

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

7 Laurie?

8 MEMBER RADWIN: So, you know, you
9 assess the whole person so you can deliver
10 individualized care. And so the test on a
11 patient's level is did they know that my
12 mother died early of cancer and now I've got
13 a cancer diagnosis? And did they titrate
14 their information, giving to me that way with
15 that in mind? And, you know, when you look at
16 what patients say in qualitative studies when
17 it gets aggregated, essentially it falls into
18 four buckets: What have I been through my
19 experiences? What do you see in my behaviors
20 now? You know, how do I feel about this and
21 how do I perceive the meaning of the illness
22 in this situation? And what you look for is

1 are you giving standardized teaching to
2 someone who has a low health literacy level?

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

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

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

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

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

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

22 MS. PACE: Yes, I think that is

1 reasonable.

2 MEMBER DUBOW: But a lot of these
3 concepts --

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

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

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

1 then other objectives that could be way
2 longer.

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

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

21 MEMBER BASCH: Are you referring
22 to the first one specifically, the whole

1 patient one?

2 MEMBER FRANK: Yes.

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

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

19 MEMBER FRANK: Well, although if
20 you're talking about the sub-component of
21 appropriate information, then, you know, there
22 are process measures. Does the care team have

1 all the information from medical visits in the
2 last two years?

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

19 MEMBER MAKAR: So just to address
20 the earlier point, I think the whole idea of
21 the timeline or this project is multifaceted.
22 Part of it is to get the conversation going

1 and get the direction moving. So I think, you
2 know, if it takes awhile to actually get the
3 measures, that that's not necessarily like the
4 total end goal. Part of it is having this
5 conversation and bringing it forward. So
6 regulation is one of the levers that ONC has,
7 but certainly we want to try to use other ones
8 as well. And you would think with something
9 like this it would be kind of do the right
10 thing, right? Find a way to do the right
11 thing.

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

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

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

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

15 MEMBER WOLFF: So in the
16 discussion today we've been talking about
17 CAHPS and I just pulled up the CAHPS questions
18 for cultural competency and there are numerous
19 questions that touch on these domains about
20 being respected, having the questions
21 answered. Does the provider care as much as
22 you do about your health? In the last 12

1 months did you feel this provider really cared
2 about you as a person? So I think some of
3 those questions already do now exist, which
4 potentially is helpful in terms of thinking
5 about next steps and not reworking the wheel.

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

16 CO-CHAIR OKUN: Okay. I'm going
17 to just throw a little provocation here. As
18 I looked at this as a provider, I was
19 wondering, well, how do I know enough about
20 the person to know that I can treat them as a
21 whole person if I'm going to be measured on
22 that? And then I looked at it as a patient

1 and a caregiver and said I need to take
2 responsibility to tell someone who I am as a
3 whole person. So I think there's again this
4 sort of flip need here when we start looking
5 at what whole person means. And I think to
6 Bruce's point most people and patients,
7 they're not going to know what that means. A
8 lot of clinicians are not going to have this
9 whole sort of sense either.

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

19 If we're going to push it forward,
20 then people need to take some responsibility
21 for being able to trust who it is that's
22 asking this information ahead of time and then

1 be willing to provide it so that the whole
2 person kind of sensibility can actually take
3 place. But that means that as a system we
4 need to provide them appropriate tools to do
5 that.

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

11 Bruce?

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

22 MEMBER MAKAR: But, Bruce,

1 honoring that, isn't that person-centered?

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

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

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

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

18 CO-CHAIR OKUN: And some of that
19 again I think we're starting to leak into
20 other concepts, too. So in the interest of
21 time, I think maybe do people feel like we've
22 discussed this one well enough for -- do you

1 feel like you have -- because the other thing
2 that we were going to do is just a little bit
3 of a touch point. Is there anything that's
4 glaringly missing from the presentation on
5 this particular concept? And is there
6 something within the concepts, the things that
7 have been presented here, where we feel like
8 it doesn't quite fit? Any thoughts on that?
9 Anything that's glaringly missing?

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

18 MS. PACE: Right. And actually
19 what we want to do, which I didn't mention --
20 so this is what you have instead of like the
21 individual sheets, right? But what we'll do
22 is put them up on the sheets back there. And

1 so for the other groups that are presenting,
2 you know, have the individual sheets, we'll
3 tape them up back there. And so we'll be able
4 to maybe during one of the breaks and at lunch
5 kind of start looking at that across the --
6 because you're right, there will be some
7 overlap and we will need to look at that.

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

15 (Laughter.)

16 MEMBER FIESINGER: I think that
17 was a positive evaluation.

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

22 Joyce?

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

13 (Laughter.)

14 MEMBER DUBOW: But I mean --

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

22 MEMBER DUBOW: Okay. But I asked

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

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

19 CO-CHAIR OKUN: I think the other
20 thing that I noticed, too, on the sheet here
21 there is a lot of nuance that's added in that
22 were put on the stickies that we didn't

1 actually go each one individually. And we
2 have to trust that the group actually took
3 some of that into consideration as we move
4 forward.

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

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

11 So that was great discussion on
12 Concept 1.

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

21 Going back to the first one, the
22 idea of having an overarching global measure

1 for this aspect. For example, I get
2 everything I need exactly when I want and need
3 it might be a PRO, or would be an example of
4 that. Or I did not receive unwanted care. We
5 fussed around with that quite a bit.

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

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

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

19 Again, in terms of the ideas of
20 what patients and sources of data and unit of
21 analysis, sort of similar to the first. In
22 general thinking about this being useful at

1 the whole system level and the clinical
2 program or meso level and then the micro level
3 in general. That was the thought. And some of
4 these you'll see we thought were amenable to
5 being either a process and a PRO or a
6 structural measure and a PRO.

7 Ethan?

8 MEMBER BASCH: I was going to
9 defer to Jennifer.

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

16 I think we felt like communication
17 was a really important piece to this, but we
18 weren't sure if some of these were overlapping
19 with another domain. But we didn't want to
20 lose sight of them, so we still included them.
21 So we recognize somebody else may have them.
22 And we thought also since we thought they were

1 important that if somebody else also has them,
2 it will show that this is something that
3 really should be looked at.

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

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

13 CO-CHAIR OKUN: Troy?

14 MEMBER FIESINGER: Okay. I'll
15 jump in. So I was looking at communication
16 and scheduling and I was thinking of how this
17 would work in my practice. So if you asked
18 us, we could say we have a patient portal, we
19 have email, we have telephone. We don't have
20 text yet. So we're doing it. But while those
21 technical social matters or measures are
22 important, what I really want to know is does

1 the patient feel that we communicated with
2 them in a convenient fashion?

3 And same thing with scheduling. I
4 could tell you about 3rd available 30 day --
5 30 minute visits, sorry. We have after hours.
6 We have weekends, blah, blah, blah, blah,
7 blah. Does the patient feel that we got to
8 see them?

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

20 (Laughter.)

21 MEMBER LEFF: So when I read the
22 draft concept "I receive the care I need, no

1 more, no less," in my academic brain that
2 sounded to me that the issue was there
3 overuse/under use, right? I don't know if it
4 was, but the inference I drew under the global
5 measure, the third individual sticky was, "I
6 did not receive unwanted care." So was that
7 the way the group interpreted no more, no
8 less? Was that unwanted? Because that to me
9 feels like a very different construct.

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

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

22 MEMBER LEFF: Right.

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

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

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

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

16 So we didn't want to make it
17 something that it was just based on evidence-
18 based, that it had some level of incorporation
19 of the patient's preferences around the care
20 that they're getting and what they choose to
21 get. So it could be something that's
22 recommended care, but they choose not to have

1 it. So we struggled with that concept a bit
2 and that's where we landed with it.

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

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

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

21 MEMBER NELSON: I think we were
22 taking this from the individual's point of

1 view, not the societal cost-effectiveness,
2 cost-benefit view.

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

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

19 MEMBER LEFF: So would it be
20 better --

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

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

6 MEMBER BASCH: You mean prefer as
7 opposed to want?

8 MEMBER LEFF: As opposed to need.

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

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

19 MEMBER LEFF: Right, but it feels
20 to me this was constructed on the construct --
21 and I'm not saying right or wrong. I'm just
22 trying to understand how you operationalize

1 it. And it feels like it was operationalized
2 as I receive the care I prefer in the way I
3 prefer -- no more, no less and I got the care
4 I prefer and the way I preferred it.

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

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

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

1 please?

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

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

1 that in there.

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

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

15 So I don't know how we implement
16 this, but I just want to say that what I know
17 now is that I want to know what my options
18 are. And it can be a concise list, you know,
19 and not just what my out-of-pocket cost is
20 going to be, but the total cost because
21 contrary to a lot of rumors, there are a lot
22 of people who say, you know, I don't care if

1 insurance is going to pay for the thing. If
2 one thing costs one grand and one costs 20, I
3 might be happy to take the \$1,000 one. So
4 knowing the available options.

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

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

21 Okay. Troy?

22 MEMBER FIESINGER: Yes, so I'll

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

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

20 CO-CHAIR OKUN: I think that's a
21 great point, because when you think about --
22 and it's sort of the concept of that label,

1 for example. So if the label actually says
2 that there's, you know, a lot of these things
3 are being considered at the systems level, it
4 should intuitively mean that those kinds of
5 nuances have been considered, that on one hand
6 the performance measure may reflect one aspect
7 of care based on some part of what that needed
8 to measure. But then on another there's a
9 countervailing balancing things that's
10 happening that says, yes, but because we're a
11 person and family-centered environment,
12 patient's autonomy overrode that. You know,
13 so it does feel like there's going to have to
14 be some of that kind of yin and yang.

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

1 (Laughter.)

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

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

16 So, you know, I think we need to
17 come back to this concept of need after we go
18 back through all the concepts. And it's
19 really about is there a match between the
20 information the patient was given, the
21 autonomy the patient had matching with their
22 preferred level of autonomy and decision

1 making, and then ultimately that the patient
2 goals were driving the process.

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

8 (Laughter.)

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

12 MEMBER BASCH: There you go.

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

18 MEMBER BASCH: Well, that's great.
19 But what I really liked in particular was this
20 idea that health concerns that the person
21 brings with them have been addressed, because
22 that's really what the patient knows. So I

1 like that way of thinking of it.

2 CO-CHAIR OKUN: Okay. Ellen?

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

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

20 MEMBER MACDONALD: It's been kind
21 of problematic for me from the beginning,
22 because it seems like -- I believe it does

1 need a more nuanced frame. It seems like
2 we're trying to put two things together, the
3 over-care, you know, or over-treatment or not.
4 And then I receive the care I need when, where
5 and how I prefer. And I just don't know how
6 realistic that part is as well. I may prefer
7 to receive my care at home, but I may not have
8 the supports that I need to be able to do
9 that.

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

22 MS. PACE: I think that's a good

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

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

17 CO-CHAIR OKUN: I think the other
18 thing that's clear to me, too, and I think you
19 raise a great point, Mary, is that this
20 actually dovetails with the, you know, core
21 where we're looking at collaborate in
22 decisions. So where you learn about my

1 preferences for location of care, for example,
2 is when we collaborate in a decision that's
3 going to need to be determined. Can I get it
4 at a home or can I not get it at home? And if
5 I can get it at home, but it's going to cost
6 me more because I need someone there with me
7 to do it, well, then I balance out that
8 decision.

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

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

1 getting what you need and what you want.

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

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

19 MEMBER DEBRONKART: I just got a
20 flash. For some reason it just dawned on me
21 that nothing I think that we're talking about
22 doing here -- all of this will apply to people

1 who are actually in the system getting
2 treatment, right? So none of this will touch
3 -- like one thing that hit me, in the other
4 countries I visited people have just been
5 stunned that pregnant women don't
6 automatically get all the care they need, you
7 know, and that newborn care isn't just
8 automatically covered and everything and, I
9 mean, with all the consequences of that.

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

20 CO-CHAIR OKUN: That's a great
21 thought. Okay. We're going to move down.
22 And we have about another four minutes or so

1 to finish up this one and we're going to move
2 onto the next ones.

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

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

22 MEMBER EAMES-HUFF: I think when

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

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

1 really good suggestion.

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

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

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

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

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

19 CO-CHAIR OKUN: Okay. So I'm
20 going to move us onto the next one, but before
21 we do, I've made a couple of notes on this
22 thing that we have assigned the different

1 groups. And I picked up from the two concepts
2 we've already talked about some commonalities
3 and things that have to do with preferences,
4 communication, convenience, information.
5 Under that options and choice. So there's a
6 lot of things I think that are imbedded in
7 these two concepts that actually are going to
8 influence some of the others as well.

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

15 (No audible response.)

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

21 (No audible response.)

22 CO-CHAIR OKUN: Okay. All right.

1 MEMBER FIESINGER: I agree Number
2 1 is a label. It also is a marketing slogan.
3 And I love my system, and my system will slap
4 that on a billboard in five minutes, because
5 that's what they do with all their quality
6 measures. So I don't it want to just be a
7 marketing slogan, because then everyone's a
8 medical home and everyone treats the whole
9 person.

10 CO-CHAIR OKUN: Yes.

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

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

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

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

1 during the break.

2 MEMBER LEPORE: We do not have a
3 handout.

4 (Laughter.)

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

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

14 One thing I do want to emphasize
15 is in the chart, which I think is useful to
16 have out, that NQF provided there, are already
17 sort of examples here. And we stayed away
18 from those, which may or may not have been
19 preferred, but they're already here and
20 documented. I think they're strong measure
21 concepts, but because they were already here
22 in the document, we did not address them. And

1 we looked to fill in additional sales that
2 were not yet touched. And in 3 and 4 this did
3 include structure and process measures, rather
4 than any outcome measures which were already
5 filled in.

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

19 And what we were thinking about,
20 you know, what sort of patients is this
21 relevant to? All. You know, we thought this
22 was pretty much relevant to all patients and

1 the data source would actually be considered
2 a clinician survey, and that this would be an
3 assessment of leadership. So really this idea
4 came from a lot of discussion about
5 leadership. It's like, okay, well, it's sort
6 a leadership system. It's a systems, or
7 systems leadership is who was being measured
8 in this culture of respect idea.

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

21 So we described it, sort of, as
22 respectful environmental design that supports

1 privacy for patients and their families, as
2 well as being welcoming for family. And this
3 also drew back to this idea of the percentage
4 of space given to waiting rooms, for instance.
5 And again, relevant for, you know, all
6 patients across settings. Thinking that this
7 would potentially be a patient survey, there
8 certainly could be an environmental assessment
9 and this is sort of an assessment of the
10 facility itself, wherever the care is taking
11 place.

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

14 MEMBER MACDONALD: Sure. So we
15 were looking at what the components are of
16 being treated with respect, dignity and
17 compassion. It seemed like an important one
18 was the amount and quality of time that's
19 being spent with me. I think we talked about
20 that yesterday, if you feel that the clinician
21 is rushed or doesn't really have time to speak
22 to you, that is -- And as you were saying

1 earlier, Sally, you know, we're talking about
2 the whole person. It's my job to tell you
3 what I needed, but with some clinicians you
4 have a sense that, you know, your 10 minutes
5 is up, and you don't really have time to
6 listen to me tell you about the whole person.

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

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

1 measure.

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

18 So high levels of elicitation,
19 checking for understanding, open-ended
20 questions and allowing people to be able to
21 respond in ways that you -- again, this goes
22 back up to time. You know, you allow me

1 enough time to be able to tell you things that
2 I need to share. Positive support, so we have
3 empathy that communicated. And legitimizing
4 who I am and what I'm saying and recognizing
5 that it has value. Bidirectional information
6 giving, so that there's an opportunity for
7 that kind of stuff to go back and forth.

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

17 Chris actually used this in a
18 couple of other examples and it's something
19 that hasn't come up, but audiotaping and
20 videotaping. Having the opportunity
21 again maybe for some vignetting, you know, to
22 be able to take the opportunity to the

1 immediately to hear what feelings and what the
2 experience was actually like.

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

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

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

1 We need to be understanding of what that looks
2 like.

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

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

15 So just getting it in an audio
16 version, versus just on a survey-type thing,
17 that it has power, it has translation that
18 people can actually appreciate. And sometimes
19 maybe in the communication piece it's also
20 done in languages that are not English, you
21 know, so that you actually have the ability to
22 translate some of that stuff about what is

1 person-centered communication and how does it
2 feel.

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

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

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

22 MEMBER LEPORE: And I certainly

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

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

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

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

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

21 There may be a cultural issue
22 that, you know, you don't make eye contact

1 with someone, but you learn that through some
2 other way, maybe that you understand that
3 person's preferences. So sometimes that's a
4 violation of someone's person, place or
5 whatever, to look them directly in the eye,
6 but that's not something you know until you
7 sort of understand the cultural issues, right?

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

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

19 The other thing, and this is more
20 of a global comment and just my impression as
21 we're talking through a bunch of these
22 concepts, yesterday a lot of the discussion

1 which made my heart sing was this notion that
2 we want to think about this beyond the center,
3 beyond the academic center, beyond the
4 hospital. A lot of the kinds of things we're
5 talking about now kind of feel very -- we're
6 going to do this in a way that will be very --
7 not even easy, but perhaps doable for those
8 kinds of centers. But remember, most care is
9 not happening there.

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

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

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

15 CO-CHAIR OKUN: I'm going to push
16 back just ever so slightly, and somewhere
17 along the way that interaction is starting
18 somewhere. So, I mean, I did community care
19 most of my career, but yet it was initiated
20 from some -- so there's some way that I get
21 into that home as a provider of sorts, right?
22 So somewhere in there, there's got to be a

1 system of some sort that's actually directing
2 that. Or, I mean, I was also an independent
3 practitioner, so I was directing myself when
4 someone would call me and ask me to come visit
5 them. So I needed to internalize some of
6 these myself, but I didn't have someone, sort
7 of, holding me accountable to that.

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

14 CO-CHAIR OKUN: Got it.

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

18 CO-CHAIR OKUN: And some of it I
19 think also may overlap into some of the
20 others, where you have coordination of care
21 and transition of care where some of that
22 should -- you know, you should have to have

1 that kind of thing transcending from one place
2 to another. But that's a big megillah thing.
3 All right. So we're going to start down that
4 end, is it? Lori?

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

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

18 MEMBER FRANK: So, and I should
19 know --

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

22 MEMBER FRANK: Well, there's a lot

1 of other principles that might come out during
2 the discussion.

3 CO-CHAIR OKUN: Okay.

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

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

18 MEMBER FRANK: Yes.

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

21 MEMBER FRANK: Right. So it's
22 patient perception, but it's much like a

1 patient's perception of whether the whole
2 patient is taken into account in the setting
3 as well. So I view it as quite similar. It's
4 global. It's arguably not specific enough for
5 this sort of a measure, but I think it's worth
6 considering that the patient perception of the
7 extent to which these principles even exist
8 and then are adhered to is worthwhile.

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

15 MEMBER FRANK: Right.

16 MS. PACE: Okay.

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

20 MS. PACE: Right.

21 MEMBER FRANK: -- more evident.

22 MS. PACE: Right.

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

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

18 As far as the privacy, I like this
19 concept a lot because again as we're pushing
20 quality measures, if I ask women for a copy of
21 their Pap smears, I get answers ranging from:
22 you mean, you don't already have it? To why

1 do I have to sign a release to get it from my
2 doctor? To why do you want it? So a whole
3 spectrum of views of privacy.

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

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

22 MEMBER DUBOW: Actually, I really

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

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

18 So I think the environmental
19 factors -- in addition accommodations for
20 people with disabilities, people who are
21 obese. You know, there's a whole range of
22 environmental things that really do reflect

1 the need to accommodate, to deal with people
2 who are getting here. And which is inherently
3 person-centered.

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

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

1 don't see it as practical.

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

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

17 (Laughter.)

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

22 But, you know, so what you put on

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

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

22 MEMBER DEBRONKART: Not sure how

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

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

20 So I hope whatever we do, it will
21 apply just as well. Because, also, in terms
22 of data, I'll bet we'll start to see it,

1 because they depend on convenience
2 essentially, you know, being a good place to
3 do business with for their business. I bet
4 we'll they are at five stars constantly.

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

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

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

15 MEMBER LEFF: Yes, Walgreens
16 will --

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

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

22 MEMBER LARSEN: As I reflect on

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

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

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

1 So just was a sort of reflection.

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

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

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

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

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

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

21 CO-CHAIR OKUN: I think you raise
22 a really important point and I trust that NQF

1 in, sort of, their landscape of what's out
2 there, too, is starting to take -- has done
3 some of that inventory, but I do think there's
4 so much to learn from -- not only work that
5 was done 20 years ago, but yet even things
6 that are being done now that sort of overlap
7 with what we're doing here. So there's just
8 a lot of resource information, a lot of really
9 smart people thinking about these things. So
10 the principles and the core values of it all
11 I think are really going to be -- we'll find
12 some overlap for sure.

13 MEMBER MAKAR: So in reflecting on
14 that conversation today, I was struck by the
15 fact that communication keeps emerging as
16 something that is, and it's not surprising, is
17 central to patient-centered care. And I
18 agreed with Lori's comment about whether or
19 not these particular core competencies are
20 necessarily -- whether or not there may be
21 some benefit to sort of looking more broadly
22 at these, at a single domain rather than

1 multiple concepts just so -- thinking about
2 communication, for example, a number of our
3 core concepts touch on dimensions of
4 communication.

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

22 And it seems like that literature

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

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

20 And I guess I'm wondering whether
21 that is part of our charge, to think about,
22 more broadly, how do we think about person-

1 centered care when it's, you know, moving
2 beyond what we know a fair amount about to
3 thinking about, you know, the person
4 experience more broadly for people who are
5 disabled and who are having to navigate the
6 social service agencies and housing. And is
7 that part of our charge? And if so, you know,
8 should we be trying to bring that into the
9 discussion more?

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

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

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

21 And then I think the challenge
22 will then be, well, we may have some measures

1 for this in some of the more, you know,
2 established institutional settings, but you
3 know what, we don't have any measures for this
4 in the retail clinics, or we don't have good
5 measures for this in home-based environments.
6 So I actually think that's exactly what we're
7 trying to get at.

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

17 MEMBER LARSEN: Yes, so I think
18 it's the latter. This is what's called a gaps
19 activity, and the idea is to really elucidate
20 where the gaps are, and help prioritize where
21 the investment should be in those gaps. It's
22 not to say that in the course of this work

1 we're going to get to all the measures that
2 we'll ever need, and we have all the
3 sophistication. That is for the next set of
4 investment. But this is to help guide us to
5 say where should that next set of investment
6 be? Where are the high-value opportunities?
7 What are things that make sense and how are we
8 sure that we're not trapped in our old
9 paradigms? How are we really thinking new and
10 different, as we make those future
11 investments?

12 CO-CHAIR OKUN: You know I just
13 want to remind us, too, one of the things that
14 I'm struck by is, you know, so much investment
15 has been made in sort of the EHR integration
16 into institutional systems and for a lot of
17 physician provider offices, but you know,
18 there's very little in the long-term care
19 setting. There's very little in the home care
20 setting. There's beginnings of, you know,
21 sort of the vendors starting to think about
22 those environments. So some of what we may

1 identify is that some of these settings are
2 not quite even ready for measures to be
3 implemented, but we may need other structures
4 in place before we can really fully help them
5 integrate different types of measures.

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

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

19 So an example of this is
20 ThedaCare, which many of you might know, use
21 their medical assistance to measure the
22 waiting times in waiting rooms of all the

1 patients in their clinics. And all they did
2 is they had the medical assistant actually
3 write on the papers schedules the waiting
4 times. And ThedaCare, over the course of a
5 year was able to virtually eliminate the
6 amount of time that the patients were waiting
7 for their providers. And they didn't have any
8 infrastructure investment other than the staff
9 they already had taking a little bit of extra
10 time to mark something that was important and
11 track and trend it.

12 CO-CHAIR OKUN: Having been
13 someone who's been in that sort of, kind of,
14 situation, where you're out there doing this
15 on your own by the seat of your pants, the one
16 thing that you end up with is sort of a really
17 great project that doesn't get up-scaled. So
18 I think we need to be careful that, yes, there
19 are things that are being done that are really
20 innovative and really great and some people
21 are really smart and doing some wonderful
22 things wherever they happen to be, but you

1 need to invest in our ability to be able to
2 bring those forth.

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

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

18 MEMBER LEPORE: Yes. Well, we've
19 experienced a bit of drift from the concept
20 here, but I think where we've gone to is
21 extremely important. And only in Concept 8 do
22 we really have this discussion of coordination

1 across settings, but even there I think we're
2 all thinking of that. And as a lot of the
3 examples show, we're thinking of that in terms
4 of coordination across care settings. But I
5 think we have, if we want to challenge the
6 paradigms that we're working in, we may want
7 to consider coordination across departments,
8 Department of Health and Human Services,
9 Department of Transportation, Housing, things
10 that are affecting people on a very grand
11 scale, these sort of inter-sectoral management
12 gaps of measurement.

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

16 MEMBER LEPORE: Right.

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

19 MEMBER LEPORE: Yes.

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

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

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

22 And the other thing I would say

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

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

11 MEMBER NELSON: Yes, I'll be
12 brief. Yesterday, Sally, you mentioned
13 sometimes we take a provider-centric view of
14 person-centered care, and what I've been
15 thinking about is: we might end up with sort
16 of a short-term, long-term approach to filling
17 the measurement gaps that will come forward.
18 And that if we looked at the promise work now
19 ten years into it, they start out with a very
20 comprehensive framework, the WHO framework,
21 and then over time they've developed great
22 measures. And it may be that we need to, in

1 the longer term, sort of, rethink the person-
2 centered care frame and start to build out
3 short-term and long-term measures that are
4 appropriate to the frame, and that capture not
5 only let's say the healthcare experience
6 across the continuum, but also social and
7 community factors as well. So that was the
8 thought.

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

17 MEMBER RADWIN: I just had a very
18 specific comment following Jennifer's example
19 of the principles of communication that have
20 been well-researched. And what it brought to
21 mind is people, clinicians and others in
22 different settings have the gift of time with

1 patients to do that great communicating. So
2 the principles that you derived about
3 physicians have also been derived about, you
4 know, my discipline in nursing, but also TO
5 and PT. And when you have the time to be with
6 a patient to listen respectfully, to hear
7 about them as an individual, to build that
8 trusting space so people can be authentic,
9 authentically represent themselves, to build
10 trust, I think we need to zoom out a little
11 bit about where the communication lives, and
12 who has the opportunity to communicate.

13 Honestly, in some of my work
14 people describe the housekeeper as delivering
15 the best patient-centered care, because they
16 were in the room, you know, and talking to
17 them, probably in a language they understood.
18 And so I think when we think about patient-
19 centeredness we have to look at all the
20 opportunities that we have to provide patient-
21 centered care. And one of the things is the
22 time to be attentive and, you know, where you

1 sit in the organization interfacing with a
2 patient can matter in that regard.

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

11 (Laughter.)

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

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

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

1 (No audible response.)

2 OPERATOR: At this time there are
3 no public comments.

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

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

14 In my own experience recently with
15 my daughter who was misdiagnosed in two
16 academic medical centers, when we got the
17 answers and got a path to patient-centered
18 care, and very important decisions about what
19 she had to do -- and the body part that was
20 important to her that she had to lose, was
21 that the surgeon spent one half-hour going
22 through everything with us. And she had a

1 busy office, but took the time to be with us,
2 and to understand what her goals and outcomes
3 -- and to hear what she had been through, from
4 a productive member of the community with an
5 important job to being non-functional and not
6 heard in the two other academic medical
7 centers. Thank you.

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

11 (Laughter.)

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

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

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

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

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

8 We're going to move to the Group 4
9 7 and 8 concepts because Bruce needs to take
10 a phone call at 11:00. And then we'll come
11 back to the Concepts 5 and 6 when he gets
12 back. Sound good?

13 (No audible response.)

14 CO-CHAIR OKUN: Okay. So,
15 Michael, you want to lead us into Concept No.
16 4?

17 MEMBER LEPORE: Great. Yes, so
18 Concept No. 4 is; we talked about this a bit
19 yesterday, I collaborate in decisions about my
20 care to the extent I desire or am able, or I
21 choose the care partner I prefer to
22 collaborate in those decisions for me. And

1 again, because we had process and outcome
2 measures identified in our existing table, we
3 really did focus again on structure measures.

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

22 This seemed to us relevant for all

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

8 The next example of a measure
9 concept we had was about patient and family
10 engagement and decisions explicitly with
11 making sure that the organization, the
12 institution has clear requirements for patient
13 engagement. And as an example of this, which
14 we're pretty enthusiastic about, is that there
15 would be recertification requirements for
16 providers tied to family engagement as part of
17 their evaluation process. So really, you
18 know, trying to back up to the sort of C suite
19 level of an organization and that there would
20 be this sort of -- a data source could be, you
21 know, documentation of conversations of
22 patient and family engagement and that the

1 institution ultimately would be defining who
2 has responsibility for this sort of measure,
3 but it would be a sort of system-level
4 measure.

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

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

15 But in any case, the core concept
16 that we went through and what I'm going to
17 present here is the elicitation of preferences
18 for collaborative decision making and sort of
19 getting at the point that not everyone is
20 necessarily interested in participating in
21 collaborative decision making, so that finding
22 some way of understanding what people's

1 preferences around that might be.

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

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

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

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

1 making took place.

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

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

18 And I put this in the construct of
19 I hear so frequently had I known then what I
20 know now. So what I want to sort of tease out
21 is do shared decision making tools help
22 patients learn what they needed to know now in

1 order to reflect back on the then when I made
2 the decision with this information and this
3 tool? I look forward and looking in hindsight
4 say that was the right decision based on what
5 I had, the information I had.

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

16 So there's obviously system-level
17 measures that would need to be in place, you
18 know, as opposed to just checking a box that
19 we've completed an advanced directive or that
20 we've actually participated in a preferences
21 assessment, that we actually show some
22 evidence of the patient actually having some

1 participation in that. Again, the patient and
2 family participating in the documentation of
3 what their shared preferences are and sharing
4 those with the clinician. So it's putting
5 some onus on the family and the patient to
6 make a decision about how collaborative they
7 want to be. And if they don't want to be,
8 okay, we recognize that. But if they want to
9 be, that we're giving them the information
10 they need and the language they need and those
11 sorts of things.

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

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

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

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

16 MEMBER NELSON: One of the things
17 I had just wanted people to be aware of; it
18 may be helpful, is that there was an article
19 published by Glyn Elwyn and others in 2013 and
20 was in the Journal of Patient Education
21 Counseling. It's a fast and frugal patient-
22 reported measure of shared decision making in

1 clinical encounters. And this is the initial
2 development results that's being further
3 validated.

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

12 But what they ended up with was
13 just three items that's meant to be asked,
14 let's say, 8 to 36 hours after a person visits
15 a clinician. How much effort was made to help
16 you understand your health issues? Item 1.
17 How much effort was made to listen to the
18 things that mattered most to you about your
19 health issues? How much effort was made to
20 include what matters most to you in choosing
21 what do next? And so that's the fast and
22 frugal measure. And they believe this would

1 apply to many kinds of regular clinical
2 interactions in an outpatient environment.

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

5 MEMBER NELSON: Exactly.

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

8 MEMBER NELSON: Yes, it's the
9 CollaborATE tool.

10 CO-CHAIR OKUN: Kevin?

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

20 So if you've read the work of --
21 oh, what's his name from the Harvard Business
22 School talking about prescription for

1 innovation that one -- Clayton Christensen.
2 One of the issues that we have in modern
3 healthcare is that we have conflated all
4 healthcare into both models of care,
5 transaction and relationship, into sort of one
6 unit of delivery. And that may actually not
7 really be very efficient or effective. And
8 some of the reasons that we do expectation
9 mismatch is people that are there for a
10 transaction don't want to wait for someone
11 else's relationship to like spill over. And
12 people that are there for a relationship want
13 more time than what that transaction has been
14 scheduled for.

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

1 what you want. So anyway, that's one tension
2 that we have.

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

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

18 So I want everything completely
19 customized to me, but I also want the very
20 best scientific evidence. So the very best
21 scientific evidence isn't completely
22 customized to you. The very best scientific

1 evidence says everybody over age 60 should
2 have X, right? And so guideline and cookbook
3 medicine actually is there for a reason
4 because it helps assure that people are
5 getting the best care that we know of in
6 science. And you can build efficiencies of
7 scale around that. If you try to customize
8 each and every one of those things to tailor
9 and fit each and every person, you run out of
10 time, frankly. So you can either be efficient
11 and deliver them as a bundle or you can try to
12 customize it all and never get to all of them.

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

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

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

20 MEMBER DEBRONKART: Just a
21 quickie. This is as meta, meta, meta as you
22 can get. It seems to me that this whole

1 endeavor and everything about shared decision
2 making and all of that is a reaction against
3 the discovery that a whole bunch of things
4 were not being done in a way that is patient-
5 centered from the beginning. I mean, I know
6 the story of the discovery in the beginning by
7 Jack Wennberg of unwarranted practice
8 variation, right? And so, the whole field of,
9 you know, shared decision making grew out of
10 trying to fix that. And in fact I imagine
11 there's Wennberg DNA in PCORI, right, because
12 that's what led to the whole idea of outcomes
13 research in the first place, you know, to
14 serve evidence-based medicine.

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

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

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

12 MEMBER DEBRONKART: Right.

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

16 MEMBER DEBRONKART: And then in
17 contrast to that I was on a call a couple of
18 weeks ago where a guy said -- he was talking
19 about medication compliance and he just said
20 flat out the problem is that patients don't do
21 what their doctor has decided is best for
22 them, you know? And it was really good for my

1 criminal history that telephones don't support
2 arms reaching through a phone wire.

3 (Laughter.)

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

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

20 There is a paper that was just
21 published this year by Alexis Turgeon in
22 Archives of Internal Medicine looking -- and

1 she found that 50 percent of hospitalized
2 older adults relied on a surrogate decision
3 maker for very important issues around life-
4 sustaining treatment. There's a large
5 literature showing that proxy decision making
6 also can be very burdensome when proxy
7 decision makers don't know preferences of
8 individuals.

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

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

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

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

1 system, right?

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

17 And, you know, the logical
18 extension of that is that their decision
19 making process is -- you know, the balance
20 between risks and benefits is probably off
21 because people don't understand the goals of
22 care. And, you know, that doesn't necessarily

1 point to a failure of the providers to explain
2 the goals of care. They very well may be. We
3 don't know. But it's a broader system failure
4 to assure that patients understand what the
5 goals of care are, you know, in order for them
6 to make decisions. So I do wonder if, you
7 know, there's a piece of that here, if there
8 are some mechanisms for assuring that patients
9 actually understand what are the goals, you
10 know? And that extends beyond advanced
11 cancers, I think.

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

17 (Laughter.)

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

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

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

21 (Laughter.)

22 CO-CHAIR OKUN: Well, all right.

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

2 (No audible response.)

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

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

13 MEMBER FIESINGER: Sure.

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

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

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

22 So we basically broke these up.

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

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

7 (Laughter.)

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

11 MEMBER FIESINGER: I would say go
12 for it.

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

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

20 MEMBER DEBRONKART: So, all right.
21 Well, the patient's experience of -- a patient
22 feeling about providers caring about their

1 time. Okay? And for which patient should be
2 included? All. But I think it will be useful
3 to segment the data by condition and by acute
4 versus chronic and by overall health status,
5 because I expect there will be significant
6 differences. Somebody with a bigger disease
7 burden or visit frequency would be more
8 affected by a good customer attitude.

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

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

22 And whose performance should be

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

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

1 was a particular clinic.

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

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

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

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

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

20 CO-CHAIR OKUN: Okay.

21 MEMBER DEBRONKART: It's a survey.

22 CO-CHAIR OKUN: A survey? I'm

1 sorry, I missed that part. Okay.

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

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

7 MS. PACE: Okay. Right.

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

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

14 MEMBER FIESINGER: Did you have a
15 suggestion, Mark?

16 MEMBER NYMAN: Should I build on
17 those comments a bit, too? And I think we
18 really just had one concept for this
19 particular core concept. And if we use that
20 same idea of respectful communication,
21 culture, environment, you could summarize this
22 as respectful of my time. And we did have

1 several different outcome -- both process and
2 outcome measures that we mentioned. And some
3 of them actually are already being measured,
4 so like your wait time in the ER and wait
5 times for appointment, but we also talked
6 about wait time for hospital discharge. And
7 a question like do you feel like they cared
8 about your time?

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

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

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

15 But we had also discussed that --
16 or today there's been discussion about the
17 granularity of, you know, is it the provider
18 or is the desk or, you know, what part of the
19 care thing? Right now when I get provider
20 feedback as a general internist, they send out
21 the survey several months after and they say
22 specifically, you know, what was the care like

1 that Dr. Nyman delivered? And then the
2 comment section will say the ENT physician
3 didn't listen to me. You know, so the
4 feedback we get isn't really specific, but
5 then in order to drill down specifically, we'd
6 have to ask a lot more questions. So I see
7 that we have a bit of a conundrum and a
8 challenge with this particular measure.

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

19 MEMBER WOLFF: So just to jump in,
20 I know Bruce would agree with you entirely.
21 And we had a sidebar conversation that
22 treatment burden was not explicitly touched on

1 in any of these constructs, but potentially
2 does fit somewhere in 2. So that's a great
3 addition, just to --

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

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

1 treatment regimen. So you can imagine cancer
2 treatment options.

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

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

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

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

22 MEMBER NELSON: I liked Mark's

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

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

1 have a comfortable conversation with the
2 provider about whom they are critical.

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

10 CO-CHAIR OKUN: I wonder --

11 MEMBER DUBOW: And actionability.

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

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

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

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

19 CO-CHAIR OKUN: Thanks.

20 MEMBER FIESINGER: So I'm going to
21 step and I'm going to take another run at
22 introducing our group. So it might be easier

1 with this email. So we basically took
2 Concepts 7 and 8. They tended to blur
3 together a fair bit. We voted on basically
4 five measures. I think the first one we just
5 talked about. Right information, right time,
6 right patient. Second, my time was respected.
7 We just talked about. The patient perception
8 of communication quality, care team to patient
9 communication bidirectionally and then
10 information access. So that's what I should
11 have said about five minutes ago. So now you
12 have it.

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

20 MEMBER CONNOR: I appreciated
21 Mark's comments about explaining to patients
22 why they are delays and communicating this

1 effectively. What we learned from our
2 patients at Dana-Farber was that they didn't
3 mind as long as we communicated with them.
4 And in fact, we had a sign on the desk if
5 you've waited longer than 15 minutes, please
6 approach the facilitator.

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

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

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

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

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

18 (Laughter.)

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

22 MEMBER LARSEN: Of course they do.

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

7 (Laughter.)

8 MEMBER LARSEN: And so we all want
9 measures that we all can get A-pluses on when
10 it turns out that maybe sort of the best
11 possible system performance in the U.S. is a
12 70 percent. But we're never going to get the
13 30 percent people to improve unless we're all
14 measuring in the same way and you can actually
15 see that there's someone able to achieve 70
16 percent.

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

21 For example, my Thursday clinic I
22 ran behind because I worked on an 86-year-old

1 who had a CHF overload because her daughter
2 gave her three slices of Red Baron's pizza for
3 her birthday. So we needed to talk about that
4 and I needed not only to treat the CHF, but
5 also tell her daughter, look, it's okay. You
6 didn't kill mom. Because she felt awful. And
7 by the end of the day I've got the Spanish
8 speaker and when I'm tired my Spanish gets bad
9 and I can't translate as quickly in my head.

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

22 My favorite line a mentor of mine

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

9 (Laughter.)

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

14 CO-CHAIR OKUN: Yes, I actually
15 think you raise a really good point, and
16 that's the perception of urgency. So my
17 perception as a patient sitting there and
18 knowing I have 10 other things to get to do
19 that afternoon and you're holding me up from
20 getting to those, my sense of urgency about my
21 need getting need is one thing. Your sense of
22 urgency over the patient who you're sitting

1 with who you clearly have a clinical need to
2 deal with is another piece. And so, that
3 information sharing I think is really an
4 important piece.

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

15 MEMBER FIESINGER: So currently
16 we're actually doing that. We have video
17 monitors, patient educational videos. I tend
18 to run behind. I send people to the lab first
19 and then see them afterwards. I try to get
20 couples together as much as possible. We're
21 actively looking at that in our practice. So
22 I think that's an excellent way to use their

1 time valuably. And my patients know also
2 bring a book or bring your laptop. Use our
3 guest wireless and do your work while you're
4 waiting.

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

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

21 MEMBER NELSON: One of the things
22 that is being learned is that if you give

1 people a choice of how to respond to the
2 survey -- so it's my smartphone, it's paper
3 and pencil, it's a speech-enabled IVR, it's at
4 home on the Web, it's the touch pad in the
5 office. Multiple channels that match the
6 person's preference goes better and you get
7 much better response rates and people are more
8 willing to share their information with you.

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

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

22 And so, those kinds of sort of

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

11 MEMBER DEBRONKART: A quick note
12 for the record. This isn't part of measures,
13 but there's something new coming along that
14 came up in our group yesterday, which is
15 consumer-friendly bits of information.
16 There's Meditoons, M-E-D-I-T-O-O-N-S, these
17 soundless videos that you can watch in the
18 waiting room. YouTube length, one or two
19 minutes. Also Khan Academy now is doing all
20 kinds of high-quality medical training things.
21 And in my ideal world a clinic would have --
22 like I would be able to log in on an iPad or

1 a kiosk in the waiting room and it would
2 record in my chart that I'd watched this, this
3 and this so that the provider would be
4 informed that I'd gotten some information.

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

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

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

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

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

8 So I think I missed Gene. Go
9 ahead.

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

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

14 CO-CHAIR OKUN: That's great. And
15 I think what it reminds us of is that we need
16 to be thinking that the technology will be
17 rapidly advancing ahead of some of the things
18 we're talking about here and that we need to
19 be sure that I think in all of the things
20 we're talking about is maximizing the
21 technology available at the time and
22 envisioning technology capabilities that we

1 may not even have yet. So, that's important.

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

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

22 MEMBER RADWIN: No, well, but it's

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

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

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

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

18 MEMBER DEBRONKART: (No audible
19 response.)

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

1 MEMBER FIESINGER: Yes.

2 CO-CHAIR OKUN: Okay.

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

7 CO-CHAIR OKUN: Okay.

8 MEMBER FIESINGER: Do you want my
9 comment now?

10 CO-CHAIR OKUN: (No audible
11 response.)

12 MEMBER FIESINGER: Well, okay.
13 I'll say it. Sorry if I went out of order.
14 So the way I would think conceptually of this
15 respect for this time was this is a tiered
16 trigger measure, meaning if you get a great
17 score, great. Don't go any farther. If you
18 get a bad score, now you got to drill down
19 into the why is it? Wait time for the doctor.
20 Wait time for radiology, lab, to get the
21 imaging test ordered. Is it that appointments
22 were scattered across time and space? So you

1 can drill down at a lot of minutiae, but to me
2 as a provider I would like some simple metric
3 that I can start with and then move from there
4 as I go through my practice improvement
5 process to figure out where the problem is and
6 how do I improve that global metric.

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

22 CO-CHAIR OKUN: And I think

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

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

21 MEMBER FIESINGER: Okay. Just let
22 me pull my notes up here. Sorry. Everything

1 locked up while I was talking.

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

17 Which patients should be included?
18 Everybody.

19 Data sources. Patient survey. I
20 don't know if Press Ganey or CAHPS had this
21 specifically. I'd have to look. But the Ask
22 Me 3 campaign came to mind where the questions

1 are: What is my main problem? What do I need
2 to do? Why is it important for me to do it?
3 A fourth one I might add, by when do I need to
4 do whatever I'm supposed to do?

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

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

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

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

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

20 (Laughter.)

21 CO-CHAIR OKUN: That's okay.

22 MEMBER FIESINGER: This did relate

1 to Concept No. 8.

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

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

6 MEMBER FIESINGER: Right.

7 MS. PACE: So what about --

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

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

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

15 MS. PACE: Right.

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

21 MS. PACE: Right. Oh, okay.

22 MEMBER FIESINGER: You can maybe

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

3 MS. PACE: Right. Sure.

4 MEMBER FIESINGER: And we just
5 lumped it all together.

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

8 MEMBER FIESINGER: No. 8.

9 MS. PACE: Okay.

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

20 MEMBER FIESINGER: So I'll
21 elaborate on that. Sorry. So basically what
22 he said. You know, complete transparency is

1 open. It's there. It's available. And again
2 it's bidirectional. The patient can import
3 information that I can read. I can put
4 information they can read. I can put
5 documents there that they may need to review.
6 They don't have to call and ask what I what I
7 told them. The classic, "Can the nurse tell
8 me what the doctor told me that I forgot
9 because my eyesight is too bad to read the
10 paper he gave to me?"

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

16 MS. PACE: Great. And just to go
17 back to the label concept, it seems like
18 something like this could be in a label in
19 terms of the category might be, you know,
20 access to records. And then, you know, there
21 could be specific information about is it all?
22 Is it just lab tests? And I was just

1 wondering if you had any conversation or
2 thoughts about that.

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

20 CO-CHAIR OKUN: I'm struggling
21 with something that actually came up in a
22 couple of other conversations yesterday, and

1 that's the notion -- when I think about time,
2 the notion of a 24/7 clock and, you know, how
3 accessible -- you know, being sure that
4 whatever we're including in these two core
5 concepts that there's accessibility when I
6 need it, too. So and that may be under 2.

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

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

20 MEMBER FRANK: Yes.

21 CO-CHAIR OKUN: Okay.

22 MEMBER FRANK: So we talked about

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

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

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

20 (Laughter.)

21 MEMBER FIESINGER: Go to the
22 emergency room. But if you think you have

1 some heartburn and you're not sure, email me,
2 but know I won't get it until I get into the
3 clinic the next morning. But if you just want
4 to know what the care instructions were, you
5 can look at that. You've got it. And then
6 you don't have to email me at all.

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

9 CO-CHAIR OKUN: Please do.

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

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

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

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

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

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

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

8 MEMBER LATTS: That's crazy.

9 (Laughter.)

10 MEMBER LARSEN: So, Lisa, I agree
 11 with you that most of this actually turns out
 12 to be organizationally-driven. ONC has worked
 13 a fair bit with this and there's actually a
 14 new FDA law that asks commercial labs to
 15 release all lab results to consumers. But the
 16 implementation has come up straight against
 17 the cultural expectations of healthcare
 18 providers which are different than the
 19 expectations of consumers. And so that plays
 20 itself out individually across healthcare
 21 systems in a very heterogenous way. So I
 22 think having some consistency of measurement

1 so a consumer could make choices, so your
2 mother could pick a different health system if
3 she wants, because she could see that this is
4 something important to her and that another
5 organization has made a different set of
6 choices.

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

12 MEMBER DUBOW: I have concerns
13 when there is a regulatory requirement to do
14 something to put it into measurement. I think
15 this is an issue around enforcement. You
16 know, it's the same thing when people have
17 access to their medical records and are given
18 a hard time in getting it. You know, it's a
19 law. And I don't think measurement should be
20 the tool, because it's too light a touch. If
21 you're entitled, you're entitled. And if
22 there's a violation obviously we have to

1 figure out -- so there should be a complaint
2 mechanism to see that you get your stuff.

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

5 (Laughter.)

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

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

13 MEMBER LARSEN: Yes.

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

16 MEMBER LARSEN: No, I'm not
17 putting it on you. I'm not putting it on you.
18 I'm saying that that enforcement -- there's a
19 lot of things to enforce. And so, people make
20 decisions about which things get a lot of
21 enforcement and which things don't get a lot
22 of enforcement. And so, it's the consumers

1 that are really going to be in the seat here
2 to help the Government say this is an area we
3 really, really need enforcement.

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

21 MEMBER LATTS: Joyce, I agree with
22 you. At the same time I think that part of

1 the overall program, the comprehensive
2 approach to this could be a look at what are
3 potential barriers to persons in our care.
4 And one potential barrier might be legislation
5 or regulation that inhibits the ability for a
6 consumer to make choices. I mean, I agree.
7 It's not NQF's role, but it is part of the
8 approach to person-centered care is taking a
9 look at what are the barriers out there. And
10 if legislation is a barrier, it should be
11 called out.

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

19 So for example, in the State of
20 New York, patients can log in to the Health
21 Information Exchange and see all of their
22 information across the whole of the providers

1 that are exchanging information in the State
2 of New York. There's no regulation that
3 requires that, but that's something that's
4 available to citizens of New York through that
5 tool. Other places like the Geisinger Health
6 System has this open notes concept where all
7 of the clinicians' notes are openly and freely
8 available through the patient portal.

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

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

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

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

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

8 (Laughter.)

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

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

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

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

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

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

22 MEMBER DEBRONKART: Oh, she was

1 probably there first.

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

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

19 So I went on Twitter and said,
20 "All right, I know this is BS. Where's the
21 document?" And within a couple of hours
22 somebody said here's the URL to this HIPAA

1 flyer. And I called back to the practice and
2 I said, okay, I looked this up. I understand
3 this is a federal civil rights violation. Who
4 do I talk to?

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

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

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

1 other mechanism for that.

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

5 CO-CHAIR OKUN: That's not fair.

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

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

18 Actually in patients like me we
19 were asked by the American Academy of
20 Neurology to ask our epilepsy patients how
21 well their neurologists were meeting the
22 guidelines for epilepsy care. And we learned

1 on one measure; and it was on surgical
2 referral, that across the board whether you
3 were an epileptologist or you were a primary
4 care practitioner, the referral for a surgical
5 assessment was really woefully low.

6 And then one of the patients on
7 the site actually had been living with
8 epilepsy for 30 years. Learned about an
9 epileptologist. So the epileptologist scored
10 pretty high compared to everybody else on that
11 one measure. Learned about an epileptologist.
12 Never heard of one before. Had been getting
13 her care pretty much from a general
14 neurologist. Went in. Asked about a surgical
15 referral. Had the assessment done. Was
16 determined to be an excellent candidate. And
17 30 years into her epilepsy is the first time
18 in her life she's been without seizure.

19 So, you know, it's that kind of N-
20 of-1 experience that not only may save a life,
21 but might also change a life. And so, it's
22 that information sharing piece that I think

1 somewhere along the way we have to figure out
2 how to be able to share that, whether it's
3 outside the system or inside the system.

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

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

20 And that's what Al Mulley was
21 referring to in "Stop the Silent Misdiagnosis"
22 published for the English audience. It does

1 apply here. And so, I think all of these
2 domains are very important and some of them
3 are really high stakes and it's under the
4 water. We don't really recognize it. We
5 don't really see it. And I just wanted to
6 mention that I think important body of work.

7 CO-CHAIR OKUN: Great. Thanks,
8 Gene.

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

11 (No audible response.)

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

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

21 So, all right. We're ready to
22 move on to Group 3. And we have a half hour

1 until lunch and so we may get just through one
2 of that. So maybe No. 5, Bruce, if you want
3 to start with that and we'll go from there?

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

6 (Laughter.)

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

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

21 The first was the notion of
22 including those that I choose. Conceptually

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

15 Thinking about the second
16 construct, this notion of supporting family
17 care partners. We had a lot of discussion
18 about this construct of what a family care
19 partner was versus what care partners were and
20 how broad that circle gets. And, you know, we
21 could think of care partners in the care of
22 say homebound elderly or disabled elderly to

1 go way beyond what we would think of in the
2 usual healthcare system. So a minute clinic
3 may be part of that system. Meals on Wheels
4 may be part of that system. A geriatric case
5 manager who's nowhere in the health system may
6 be part of that person's system. So we talked
7 about all those things quite a bit.

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

21 So the notion of, you know, could
22 there be structural IT things built into a

1 system to help in terms of this notion of
2 supporting family care givers? Could the
3 notion of structure, the relationship that an
4 entity has with appropriate services to
5 support the family care partners -- and that
6 could be practice and non-practice-based. So
7 just trying to think about it in a very broad
8 ecosystem of care.

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

19 (No audible response.)

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

1 (No audible response.)

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

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

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

19 MEMBER RADWIN: Yes, I mean, we
20 talked about if you have a document -- if the
21 clinician document is an assessment of the
22 care partner or the family caregiver. That's

1 not a burden on the caregiver to respond. You
2 have a document assessment. It's a process
3 measure I'd assume. And I supposed you'd have
4 standards of completeness for the domains that
5 you assessed. Does that answer your question?

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

18 But actually the second one is
19 almost more interesting. It's that the system
20 is much less likely to be gained if we're
21 using data that's collected for the primary
22 purpose of really good care delivery. And we

1 can secondarily measure that that really good
2 care delivery happened. So when we introduce
3 measurement just for the sake of measurement,
4 we actually introduce all sorts of reasons for
5 bias and confounding just because what we're
6 doing is measuring for the sake of measuring.

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

18 "Caregiver assessment is a
19 systematic process of gathering information
20 about a caregiving situation to identify the
21 specific problems, needs, strengths and
22 resources of the family caregiver as well as

1 the ability of the caregiver to contribute to
2 the needs of the care recipient."

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

15 So to take a step back from that
16 though and to think about caregiver assessment
17 as part of a healthcare or long-term care
18 process, there are some measures that have
19 been developed like the CARE tool that was
20 developed by CMS for transitional care for
21 patients as they move from setting to setting
22 where there is an assessment of the patient's

1 perceived network of people who are caring for
2 them, but the caregiver is not specifically
3 talked to. So it's the patient's perceptions
4 of the caregiver's ability to provide needed
5 care on discharge for the hospital, as an
6 example.

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

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

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

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

1 apart.

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

4 Annie?

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

17 CO-CHAIR OKUN: I think the other
18 thing this lends itself to is really giving --
19 it speaks to the efficiency and utilization of
20 my time. So as a caregiver allow me to do
21 some assessment of my abilities in the time
22 frame that's useful for me and not necessarily

1 on your time frame. So being able to do that
2 on my own time or on the computer or on
3 different modalities would be important.

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

16 The experience I have building
17 measures for this actually comes in
18 pediatrics. We're working to build a measure
19 of screening mothers at children's postnatal
20 visits for perinatal depression symptoms. So,
21 the caregiver is the mother, but the visit is
22 the baby's. And I think everyone can

1 understand why perinatal depression treatment
2 is actually the best thing for the baby, not
3 just for the mother. So it makes really sort
4 of logical sense there, but I'll tell you that
5 the operational and patient privacy hurdles
6 are really high, which doesn't mean we
7 shouldn't forge ahead, but it's forge ahead
8 and say that it's really important.

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

22 So it feels like there's an

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

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

9 (Laughter.)

10 MEMBER FRANK: So the
11 uncoordinated one.

12 (Laughter.)

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

1 involved and then what are the measures around
2 that?

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

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

21 And so I think it would be, you
22 know, a similar movie would be what would our

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

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

19 MEMBER LEFF: So No. 6, my care
20 partners provide information in a format I
21 prefer to answer my questions, help me
22 understand my choices about my health, health

1 problem, treatment care, costs, or providers
2 and increase my confidence in capacity to care
3 for myself to the extent that I am able.

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

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

1 around that construct.

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

14 Anything the group would like to
15 add to our --

16 CO-CHAIR OKUN: Anything, others?

17 (No audible response.)

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

1 well.

2 Troy?

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

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

18 MEMBER RADWIN: When I was going
19 through it, it felt more like an outcome, you
20 know, and the burden in this sector, this
21 concept is the burdens around -- the emphasis
22 on information leading to self-efficacy

1 sometimes -- you know, it's every educator's
2 burden. If you just taught them the right
3 way, they'd be able to do this. And that's
4 not the only thing that leads to competence or
5 capability in self-care. And, Sally, when you
6 said it felt different, that's the reason it
7 felt different to me. It's an outcome that
8 can be influenced by information sharing, but
9 it's necessary, but it's certainly not
10 sufficient. And so I'm wondering if it even
11 has a place there.

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

17 Yes, Karen?

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

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

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

15 CO-CHAIR OKUN: So there's one
16 thing though that is striking me here and that
17 is what you mentioned before, that it's not
18 simply information that we provide that
19 increases someone's ability to have some self-
20 care capacity, right? So it feels like we've
21 confounded the ability and capacity and the
22 confidence to be able to care for self to the

1 degree I'm able with the delivery of
2 information. Do we all agree that we need to
3 separate those two?

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

1 the --

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

4 CO-CHAIR OKUN: Gene?

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

16 And of course with chronic
17 conditions, especially high-impact and
18 multiple comorbidities, I live with it
19 24/7/365. And we know from the work of
20 Bandura and Lorig and more recently Wasson
21 that outcomes are better when self-efficacy is
22 high, that satisfaction is higher with my care

1 team when self-efficacy is high, and outcomes
2 and costs are better.

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

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

22 MEMBER DUBOW: I agree. In

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

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

21 MS. PACE: Where you saw it was on
22 the sample framework as a potential outcome

1 measure. But just so you know, I've heard
2 that the patient activation measure is going
3 to be brought to NQF for consideration.

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

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

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

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

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

21 MEMBER FRANK: So I think that
22 6(b), if that's what this is, should come out

1 separately. I think it's about supporting an
2 individual as an agent in their own care. You
3 could break it down and make it more
4 measurable by focusing instead on supporting
5 the patient as a decision maker in their
6 decision making about their own care.

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

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

20 CO-CHAIR OKUN: Yes, and at times
21 where decisions weren't necessarily needed to
22 be made. Decisions may have already been made

1 collaboratively, but now I'm going out and I'm
2 exercising what I need to do to be confident
3 in my ability to do that. But I can see how
4 you see them sort of linked, but --

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

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

12 MS. PACE: Will patients relate to
13 that term?

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

17 But coming back to a lot of the
18 points you've been making about -- I think
19 this notion of agency does allow for a
20 virtuous circle where people will become more
21 involved, and it should. You know, this feels
22 like a higher-level thing that if it could be

1 influenced can really percolate through a lot
2 of the constructs that we've been developing.

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

12 MEMBER RADWIN: Two concepts again
13 from some qualitative literature: One of the
14 things that patient-centered care provides by
15 sharing knowledge of a trajectory of a disease
16 or of other patients in circumstances like
17 your own. I mean, clinicians do that, too.
18 Patients do it for each other, but you know,
19 we hear, you know, if you're going to get this
20 kind of chemo, the nurse will tell the patient
21 you're going to be down and out for two days.
22 You're going to feel like you're something and

1 then we're going to whack you again. You
2 know, that trajectory of an issue helps a
3 person develop insider expertise. That's
4 Jerry Lam's finding.

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

16 MEMBER LARSEN: So I want to move
17 to the information one, and I want to be sure
18 that we don't under just some big rubric lose
19 the good work we've done at sort of specific
20 sub-areas of information. And so that as I
21 think about how they've kind of played
22 themselves out, the one we talked about most

1 predominantly in the No. 8 was my information
2 is available to me and my family. So that's
3 about my own personal information that has
4 been collected, labs, whatever it is.

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

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

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

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

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

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

20 MEMBER DUBOW: I don't know
21 myHealthcare Cost Estimator, but I think we
22 need to think about not the one-off, sending

1 people off to these things when there are
2 tools that factor all of the pieces of
3 information in one tool. Krukoff has done
4 this. So that when you are making a selection
5 of a plan, you can sort by the factors that
6 you are most interested in. It's absolutely
7 patient-centered. Some federal employees have
8 access to this. I don't know which agencies,
9 but there are a few of them that use it. So
10 you can sort by quality, by physician, by
11 cost. There are actuarial estimates about
12 what your out-of-pocket costs are going to
13 look like based on utilization experience.

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

21 CO-CHAIR OKUN: So that feels a
22 bit like a long-term objective of gathering

1 the data from -- in a short-term way looking
2 at all the potential sources and then long-
3 term having one place where someone could go.
4 And as a provider or care partner part of my
5 job is to be sure that my patients are able to
6 get access to that information?

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

18 MEMBER LARSEN: And I think this
19 is where the nutrition label idea could really
20 be of use. So there's going to be a
21 proliferation of tools, and there should be.
22 And there should be some variance in what

1 different components are. But to really have
2 a consistent experience by which a patient
3 could expect to interact with that information
4 across lots of different kinds of places,
5 application sites, so that they know calories
6 are here, serving size is eight ounces, I'll
7 get the saturated facts pulled out separately.
8 That's my out-of-pocket cost pulled out
9 separate. There's some expectation for a
10 standardized format for how the information is
11 pulled together, which allows for diversity of
12 programs, plans, reasons, et cetera.

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

22 CO-CHAIR OKUN: I don't see any

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

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

12 But definitely good work, good
13 ideas and you deserve a lunch break. We were
14 contemplating working through lunch and you
15 actually get to have lunch. So let's take a
16 half hour for lunch, reconvene at 1:15 or
17 1:20. We'll summarize and we'll see where
18 we're at. Thank you.

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

1:18 p.m.

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

(No audible response.)

OPERATOR: At this time there are

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

1 everyone. But we'd like to just go around the
2 room and ask each of you to maybe weigh in or
3 make some observations or comments about
4 short-term versus long-term, things that you
5 think are kind of ready to move on now versus
6 things that are going to be on a longer
7 trajectory.

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

15 But Gene had actually three
16 recommendations, and these probably -- I think
17 this first one is actually more of a longer-
18 term. He referred to it as measure cascades.
19 And his idea, which he already mentioned, is
20 the Person-Centered Care 10 like the PROMIS-
21 10. So his idea is, you know, really to work
22 with a group like PROMIS and actually develop

1 that kind of instrument where all of the
2 concepts can be measured and drilled down into
3 sub-concepts. So that was one of his
4 recommendations.

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

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

1 cetera.

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

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

21 And just a place that we can look
22 for data, you know, I can just say that

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

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

20 MS. PACE: Thank you.

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

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

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

14 MS. PACE: Maureen?

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

1 missing something that's available.

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

7 MS. PACE: Michael?

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

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

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

13 MEMBER WOLFF: So I have three
14 points that all sort of touch on the non-
15 standard patient. I think, you know, we
16 already have a number of measures that are in
17 place, and I think it's great to build on
18 CAHPS and PROMIS. I guess I would love to see
19 a lot of focused work outside of the easy,
20 healthy population, populations that may not
21 be able to answer CAHPS by themselves. For
22 example, how do we think about quality of care

1 for the patients that Bruce sees in clinic,
2 that are really challenging, and really
3 thinking about what does quality care mean for
4 them?

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

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

21 And so, in the discussions over
22 the last couple of days it seemed as if there

1 was some support for two pieces that address
2 this: Number one, specifically eliciting
3 patients' preferences for family involvement
4 and having that being supported by their care
5 partners. And then secondly, some level of
6 system responsibility for eliciting and
7 addressing the needs of family caregivers when
8 the care plan is reliant on that family care
9 partner.

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

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

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

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

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

9 The other thought experiment to do
10 -- and I don't have this answer to this, so
11 I'll just pose it. So with a food label, are
12 we suggesting that if we set up a health
13 system, however you want to define a health
14 system, in a place that goes unnamed, and we
15 brought a group of New Yorkers to get care in
16 that system, and then we brought a group of
17 people from South Central LA and we brought a
18 group of, you know, people from Portland,
19 Oregon, are we suggesting that all of them
20 would rate the care experience the same even
21 if their illnesses were the same, just by
22 virtue of culture and all of that? So think

1 about how all of those influences on ratings
2 and sharing of ratings go. I think that's not
3 --

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

10 MEMBER LEFF: Okay.

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

16 MEMBER LEFF: That makes me feel a
17 little better about all of that. The other
18 thing, as you move forward, I think it's
19 really important to think about how this gets
20 implemented in a care system that's evolving
21 very rapidly. Very rapidly. So I really
22 believe, if we're just thinking about typical

1 settings of care, we're going to be at a
2 disadvantage 10 years from now, 15 years from
3 now. I mean, I would really think about
4 Walgreens and CVS as a primary care delivery
5 system, and actually potentially as a data
6 gathering system, right? That's a place where
7 you can gather data as well. Really think
8 about practicality of these measures and don't
9 just -- I think if we're going to go for
10 something just because it has face validity,
11 and we don't know that it really will affect
12 outcomes, then we're going to be in trouble.

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

22 MS. PACE: Cille, do you want to

1 make any comments? No?

2 MEMBER KENNEDY: (Off microphone.)

3 You mean I wasn't yelling loud enough?

4 (Laughter.)

5 MEMBER KENNEDY: Oh, dear. Okay.

6 I'll pull it close. And you just wanted me to
7 thank you a second time?

8 (Laughter.)

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

18 MS. PACE: Ellen?

19 MEMBER MAKAR: So I think that
20 this has been a really fun couple of days. I
21 think this work is really difficult because
22 it's so abstract and it's tough to wrap your

1 head around it. So that said, if we're having
2 a hard time with it, I think others will as
3 well, so I think it's important to keep that
4 in mind.

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

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

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

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

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

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

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

20 And then, you know, what I like
21 about the Person-Centered 10 is, to me, it's
22 a way to get at this notion of ensuring that

1 there's some measurement of whether principles
2 of person-centered care are evinced in the
3 care an individual receives.

4 MS. PACE: Okay. Thank you.
5 Troy?

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

16 This is kind of a mix of short and
17 long-term, but I still am not quite clear on
18 our global concepts versus measures. And I
19 was trying to make a little spreadsheet to
20 realign things, and we have concepts like
21 respect, choice, dignity and a lot of stuff
22 falls into that. And maybe you already plan

1 to do this, but I'd like to have some process
2 to kind of realign and reorganize things, as
3 I think you had said, Maureen, in a way that
4 makes a little bit more sense, conceptually,
5 so that I know where a label is going.
6 Because I'm thinking if I'm trying to present
7 the label to the family docs in Texas, what's
8 this? Why? So having the goal in mind,
9 knowing what it's going to say, what it's
10 going to do for them is important.

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

1 possible. That's always a compromise, but I
2 think that's a goal to shoot for.

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

17 MS. PACE: Joyce?

18 MEMBER DUBOW: So I do add my
19 thanks to the staff and to everybody here. I
20 think it was a really good group. I
21 appreciate having had the chance to
22 participate. So I have a list on my napkin

1 here. It's a jumble of thoughts.

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

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

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

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

3 MEMBER DUBOW: Right.

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

6 MEMBER DUBOW: Right.

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

9 MEMBER DUBOW: Yes.

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

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

17 I think we need to address the
18 continuum of care. I think the unit of
19 analysis, we should not be assuming
20 necessarily that this at the physician level,
21 or at the practice level for that matter.
22 There are many units of analyses. It doesn't

1 have to be a physician office responsible for
2 providing information in a certain way. That
3 could be a health system. It could be a
4 health plan. We have to think about all of
5 the units of analysis that would be relevant.
6 So, I think we shouldn't think silo. I think
7 we should think broadly.

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

16 I don't think they -- I hate the
17 expression to give them permission, but, you
18 know, that's the trite way of saying that we
19 need to help them understand that they have
20 rights, and should be asserting them within
21 the healthcare system, and reasonable
22 expectation this is the way care should be

1 provided. They need to learn that through the
2 kinds of measures that we put forth. So I
3 think that's useful.

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

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

1 So I think that's my notes.

2 Preference for outcomes. Okay. Thank you.

3 MS. PACE: Dave?

4 MEMBER DEBRONKART: So, let's see.

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

15 Second, it's so important, I think
16 it's going to be so essential -- and we may
17 have to approach this at the level of
18 leadership. You know, maybe we want to have
19 some sort of a CEO-level gathering, or maybe
20 we have small regional meetings where we bring
21 people together, because my understanding is
22 that C Suite people prefer not to have their

1 issues and especially their garbage discussed
2 in public, but say, look, you guys; and I mean
3 guys in an omni-sex way, a lot of these things
4 have been solved. It is causing harm that
5 your people aren't doing these things. So we
6 got to do something about that.

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

16 You know, like in their book
17 Switch, one of the stories was about in post-
18 war Vietnam many, many kids were malnourished
19 and there were many, many knowledgeable people
20 who had expertise in why it is unsolvable.
21 And the only way out of it was they found some
22 isolated areas where the kids were not

1 malnourished, and they figured out what was
2 different there. And I see that here also.
3 The fact that some people have solved these
4 things. Virginia Mason has no more waiting
5 rooms, things like that.

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

17 Well, and I understand why. I
18 mean, how would I know? Here I am. I'm
19 diagnosed by geniuses with of all a sudden,
20 dude, out of nowhere you've got stage 4 kidney
21 cancer. What do we do now? I depend on those
22 geniuses and their expertise. And I'm not

1 dissing that in any way, but it's this giant
2 missing voice. And I have one anecdote on
3 that that is very moving to me. I don't think
4 I mentioned it yesterday. Did I mention the
5 Dutch IVF clinic, in vitro fertilization?

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

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

20 And what they came back with, the
21 first two, of course, were to have insurance
22 cover more attempts. But then the number

1 three, the top thing other than a baby, all
2 right, was empathy from their providers. Not
3 just information. Empathy. And the number
4 four thing was separate waiting rooms for
5 families who've conceived, so that the ones
6 who haven't don't have to be confronted with
7 it, you know? And then the fifth thing on the
8 list was the thing that everybody talks about,
9 more convenient appointment times.

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

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

20 I would emphasize trying to keep
21 the core concepts simple, so they're easy to
22 understand. And I know we have a tendency to

1 try and explain all the nuances to different
2 things, and I think that in the end may do us
3 a disservice, that the nuances can be captured
4 in the measurement and what comes out from
5 that. And we need something that's easily
6 explainable.

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

16 And I do think there's a lot
17 already out there, as well as what's in this
18 room. So culling from that I -- the shorter
19 versus the longer, it's hard to say one or the
20 -- I think there are things that you can -- I
21 see two streams. There's the working on some
22 things to get some shorter-term things in the

1 pipeline, and also the longer-term, developing
2 that. And that would be it -- and thank you.

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

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

20 And we had really, I think, a lot
21 of breakthroughs in rich and open discussion.
22 So I think that's a sort of larger

1 recommendation this group could make in
2 general, as we move to influence lots of
3 measure prioritization and measure
4 development, is that we need to do it this
5 way.

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

18 As far as kind of specific
19 outcomes, things that I think would be helpful
20 as we move forward in the next phases of this
21 type of work. The framework is fantastic, and
22 I think, again, crisp framework that is really

1 easily understood by patients would be
2 terrific.

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

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

20 And then, from a prioritization
21 standpoint, I think there are two areas of
22 prioritization that would be helpful. One

1 really for us at HHS, which is, what are we
2 ready for measure development? You know,
3 which things are next as we start doing
4 contracts and projects? And again, don't just
5 think about individual physicians.

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

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

20 But there's another prioritization
21 I think that we need to call, out and this is
22 maybe more to Lori or others, which is: we

1 need research. Because one thing that I've
2 been learning, as we're trying to fill these
3 measure gaps in measure development constructs
4 is that many times we're actually missing some
5 of the basic research that would really set us
6 up for success to do the right kind of
7 measurements in these areas. And again, HHS
8 has a lot of the kind of opportunity and
9 resources where we do fund a fair bit of
10 research.

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

20 Also continued sort of call- out
21 to the group. Help us be creative to reuse the
22 data we already have, because for the reasons

1 that I mentioned, it's less easy to game, and
2 the burden is really not as present.

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

15 So on a Friday afternoon dad went
16 in for a biopsy. They thought it was going to
17 be benign. And by Friday evening the
18 pathologist had read it and called him and
19 said it was cancer. He had an appointment
20 with his primary care doctor on Monday
21 morning, so I went with him. We waited in the
22 waiting room for about two minutes. The

1 doctor was in the room about three minutes
2 later. Had a terrific conversation with my
3 mom and my dad and I. And he said, you know,
4 I think you should see an oncologist. Where
5 would you like to go? And dad said, well, I
6 think I'd like to go here in town. And so his
7 doctor said, sure, let me see what I can do.
8 Left the room.

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

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

1 they handed us the CAT scan image. We went to
2 have lunch.

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

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

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

22 And how are we sure that we're

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

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

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

21 MEMBER FRANK: And this is Lori.
22 I just want to add regarding the call for

1 research. I think there's a great opportunity
2 here for some partnerships. PCORI has already
3 funded a lot of projects on patient
4 preferences regarding care and information
5 provision and care partnering. And we're
6 interested in continuing to do so, and always
7 interested in collaborations or partnerships
8 with other groups where we can help jointly
9 advance agendas.

10 MS. PACE: Laurie?

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

21 And so when we look to existing
22 measures, I think we have to be highly

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

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

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

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

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

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

12 (No audible response.)

13 MS. PACE: Okay.

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

19 So I would like to sort of -- a
20 couple of practical things, test our
21 assumptions about definitions and vocabulary,
22 and just be sure that we're feeling confident

1 that we've captured those well, and where we
2 think they're still open for discussion, start
3 thinking about what needs to be more
4 clarified.

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

13 I also want to think about working
14 hard on the outreach for public comment on
15 this, because I think, you know, we didn't
16 have any comments at all throughout the course
17 of this. And so I think we need to find
18 different ways for NQF to reach the public in
19 a way that we can actually broadcast, and be
20 sure that people are hearing the next phase of
21 this. So, please, certainly we'd be happy to
22 make some -- and I'm sure Dave would be happy

1 to do some tweeting, but I think there needs
2 to be some greater opportunity to reach real
3 people.

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

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

19 And ultimately I think you've
20 heard my talk on this in the past, but I think
21 we absolutely need to start moving this into
22 the public domain so that people can begin to

1 appreciate that they have a role, and they may
2 even have some responsibilities, and we need
3 to get input from them about what that balance
4 is like. Some of that can get reflected in
5 some of the work being done with team-ness,
6 with patients actually being part of the team
7 and being a member of the team. But really
8 bubbling that notion up I think is only going
9 to help us really push this along.

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

15 MS. PACE: Okay. This is just to
16 let you know, kind, of next steps, which is
17 not on here. Obviously we have a lot of
18 review and synthesis to do. And, you know,
19 certainly the rich discussion will help us
20 with our co-chairs and advisory group, help
21 revise the core concepts and, you know, I
22 think definitely to lay this out according

1 those. But we will then have a draft report
2 available, first of all, to this Committee to
3 review, and then it will be open for member
4 and public comment.

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

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

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

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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

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