

NATIONAL QUALITY FORUM

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PERSON-CENTERED CARE AND
OUTCOMES COMMITTEE MEETING

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MONDAY
APRIL 7, 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 9:00 a.m., Sally Okun and Uma Kotagal, Co-Chairs, presiding.

PRESENT:

UMA KOTAGAL, MBBS, MSc (Co-Chair)
Cincinnati Children's Hospital Medical Center
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
CHRISTOPHER FORREST, MD, PhD
The Children's Hospital of Philadelphia, University of Pennsylvania
LORI FRANK, PhD, Patient-Centered Outcomes Research Institute
PRITI JHINGRAN, BPharm, PhD, GlaxoSmithKline

CILLE KENNEDY, PhD, ASPE
KEVIN LARSEN, MD, Office of the National
Coordinator
LISA LATTS, MD, MSPH, MBA, FACP
LML Health Solutions, LLC (via
teleconference)
BRUCE LEFF, MD, Johns Hopkins University
School of Medicine
MICHAEL LEPORE, PhD, Planetree
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

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 9:07 a.m.

3 Welcome and Introductions

4 MS. PACE: Okay. Good morning
5 everyone. Thank you for being here on this
6 great morning, but I guess we won't be longing
7 to be outside. So maybe that's a good thing.
8 So we welcome you to our meeting on person-
9 and family-centered care, and we want to start
10 out with introductions.

11 We've built in some time this
12 morning for introductions, for you to
13 introduce yourself and, you know, where you're
14 from, the typical things. But we'd also like
15 you to really make some comments about --
16 share some of your views on receiving,
17 delivering and/or measuring and person- and
18 family-centered care.

19 So just, you know, kind of where
20 you're coming from, as we go into this meeting
21 and this topic. We have, you know, a whole
22 set of panels and presentations and discussion

1 groups for us today. But we thought it would
2 be good for everyone to have a chance to just
3 kind of lay out their most important things
4 for all of us to understand and share where
5 we're coming from.

6 So I'm going to pass it on to our
7 co-chairs to make some opening remarks, and
8 introduce themselves, and we'll just move
9 around the table.

10 CO-CHAIR KOTAGAL: Good morning.
11 I'm Uma Kotagal.

12 MS. PACE: One logistical thing to
13 start with is that we ask that you speak into
14 your microphone, and we can only have, I
15 think, a couple on at a time. So when it's
16 on, it will be red and I think you'll see the
17 red around the rim there as well.

18 CO-CHAIR KOTAGAL: Good morning.
19 I'm Uma Kotagal. I'm a pediatrician at
20 Cincinnati Children's and direct the
21 transmission work there. I'm a health
22 services researcher, and we have been pursuing

1 and thinking a lot and learning about patient-
2 reported outcomes, how they've changed how we
3 do our work, how they've changed how the team
4 functions. So I'm delighted to be here.

5 CO-CHAIR OKUN: Hi. I'm Sally Okun.
6 I'm from PatientsLikeMe. For those of you who
7 may not be aware of us, we're a web-based
8 platform research-based platform for patients
9 to monitor their own health and connect with
10 each other.

11 I'm thrilled to be here. My
12 background is as a nurse. I really came into
13 measurement more recently in the last eight
14 years, since I've been with PatientsLikeMe,
15 where I see the incredible value of gaining
16 insights from patients, to really understand
17 the experiences that they have, and ultimately
18 the outcomes that they're experiencing.

19 So being here and starting to think
20 about patient and family, person- and family-
21 centered care, and how we can begin to measure
22 that and then measure the performance against

1 it is incredibly important to me.

2 However, I would preface it. I am
3 not a methods or measures expert, so my role
4 as the co-chair here is to learn as much from
5 you all talking about this, but also to bring
6 that patient perspective. Hopefully maybe
7 that might give you some insight. So thank
8 you very much for having me.

9 MS. PRINS: Good morning, everyone.
10 I'm Wendy Prins. I'm with the National
11 Quality Forum and I'm really happy to be here
12 today. I'm helping to oversee our various
13 projects focused on measure gaps this year,
14 and this is of course on top of mind to a lot
15 of people, really how do you measure the
16 things that are important to patients.

17 We have a lot of work going on at
18 NQF related to this. I think four, Michael
19 pointed out four different projects that you
20 found on our website. So happy to help
21 clarify any of those for you today, and let
22 you know kind of how they're tying together.

1 DR. ADAMS: Good morning. I'm Karen
2 Adams. I'm Vice President here of Strategic
3 Partnerships. I know I've had the good
4 fortune to work with many of you around the
5 table on various projects related to patient-
6 and person-centered care. I'm just so
7 grateful you're here today, to have so many of
8 you take time away to work on this is just so
9 important.

10 You have a great team with Karen and
11 Wendy and Mitra. I know there's many Karens
12 here. Ethan, I think, when we were working,
13 Karen, Karen and Ethan.

14 But please, just know how much we
15 appreciate this. I think as Wendy pointed
16 out, this project really is part of a bigger
17 whole, and not only the work around NQF
18 working on person-centered care, but also we
19 try to work very closely with the Institute of
20 Medicine and other groups who are working,
21 Cory, etcetera.

22 So I think it's very important in

1 your role, as you're working on different
2 work, that we can bring this together and
3 coordinate. I'd be happy to speak to you
4 about that more offline. Thank you.

5 MEMBER BASCH: Good morning. I'm
6 Ethan Basch. I'm a medical oncologist and a
7 health services researcher at the University
8 of North Carolina in Chapel Hill.

9 I run a research program focused on
10 patient centeredness and patient-reported
11 outcomes, and work with a number of agencies
12 developing standards around delivering
13 patient-centered care and conducting patient-
14 centered research, and I'm excited to be here
15 as well, and look forward to learning from our
16 discussions.

17 I would note that as both a
18 clinician and as a clinical investigator, I
19 frequently find myself frustrated that both
20 the care that we deliver and the way that we
21 conduct research is not patient-centered
22 particularly. We do not take into

1 consideration the perspectives of patients.

2 My observation is that actually
3 interferes with our ability both to deliver
4 the care that is appropriate for a given
5 patient, and to conduct research in a way that
6 actually addresses the decision-making needs
7 of patients.

8 MEMBER RADWIN: Hi. I'm Laurie
9 Radwin. I'm a registered nurse and a health
10 services researcher with the VA, and my
11 interest lies in patients' perceptions of
12 patient-centered nursing care, and I've
13 developed a couple of scales that are in use
14 on that.

15 I started out with qualitative work
16 of interviewing patients, and then I built
17 scales from those. As I looked over the
18 materials, I think our challenge is really to
19 use the concepts and constructs that we've
20 been discussing, to find them sufficiently
21 bounded, such that they can be measured well.
22 So I'm looking forward to the work.

1 MEMBER LARSEN: Kevin Larsen. I'm
2 excited to have you here. I'm the Medical
3 Director of Meaningful Use at the Office of
4 National Coordinator of Health IT. We're the
5 sponsoring group. A little bit more about
6 that later. This is personally really
7 exciting for me, to have so much time and
8 energy focused on this really important area.

9 I spent part of my life as a health
10 services researcher, and back in medical
11 school, stumbled upon a terrific mentor, who
12 had started a project looking at Medicaid
13 patients and what happened to them as the
14 Medicaid program in California changed its
15 eligibility, and had the remarkable insight to
16 follow people and see what happened to people
17 as they lost insurance, as opposed to thinking
18 about statistics.

19 It turned out that when you followed
20 people, they had really dramatic impact to
21 changes in health policy. From the window of
22 health services research, where you always

1 just look at claims or you look at a specific
2 site of care.

3 You lose track of the people, and
4 you don't know that what happened to them. So
5 part of the reason I got into actually health
6 care IT was this idea that we could really
7 study the impact of how systems worked,
8 because health IT, we have the opportunity to
9 not just look a claims; we have the
10 opportunity to look at information, about
11 people as they see care and clinicians
12 wherever they go; and even beyond the clinical
13 settings as they live their lives.

14 So excited about this work, excited
15 about its impact for measurement, but also
16 excited about its larger impact and how we can
17 help improve the health care system, with this
18 more focus on the people as they experience
19 their care.

20 MEMBER deBRONKART: So I'm Dave
21 deBronkart, known on the Internet as ePatient
22 Dave. For those who don't know it, the "E"

1 stands for Empowered, Engaged, Equipped,
2 Enabled, and seven years ago this month I was
3 dying of Stage 4 kidney cancer, and along the
4 way, in addition to getting great medical
5 care, I did everything I could to help myself
6 via the Internet, connecting with other
7 patients and so on.

8 Through a strange series of
9 circumstances, it's turned into a full-time
10 job. Well not a job. I mean I'm on my own.
11 I've got no salary, I've got no etcetera,
12 etcetera.

13 But I travel around evangelizing for
14 what would be possible in better health care
15 outcomes if the system truly gave people the
16 information they need, and access to all the
17 information in the world, so they could help
18 their doctors and researchers.

19 I have -- Ted talked in a book
20 titled Let Patients Help. I don't assert that
21 even well-informed patients are oncologists.
22 I'm also something, having worked in IT in

1 most of my life before this, I'm something of
2 a bugger about data quality. Just five years
3 ago this week that I wrote a blog post about
4 my medical record containing garbage that
5 ended up on the front page of the Boston
6 Globe, which led to me testifying on
7 meaningful use and all kinds of things.

8 It's ironic that the reason I'm late
9 is because I had wrong information on where
10 this was, which kind of makes the point.

11 MEMBER NELSON: Good morning. Gene
12 Nelson. I'm at Dartmouth Institute and
13 Dartmouth-Hitchcock, and work in the
14 Population Health program there. Very, very
15 interested and committed to finding ways of
16 improving and innovating health care and the
17 outcomes that people want, very interested in
18 the design of full health systems and front
19 line systems that put the individual patient
20 person at the center, and that everything
21 flows from that, and the design of information
22 and measurement systems actually support care

1 as it's delivered and people living, their
2 health and health conditions.

3 MEMBER DUBOW: All right. I'm Joyce
4 Dubow from AARP. We have about 39 million
5 members, half of whom are between 50 and 64.
6 The rest of them are over 65. Clearly, these
7 are people who use health care a lot. Many of
8 them have chronic conditions. We have a
9 health care system that needs to be
10 transformed, and to sound trite, to put people
11 at the center of it.

12 As a policy matter, I think we have
13 a huge way to go, but measurement can help.
14 I think our task is to identify those parts of
15 the patient experience that ought to be
16 measured, so that we can see how we're doing
17 and so that we can use those ideas to improve
18 care. So I hope we achieve that.

19 MEMBER FIESINGER: I'm Troy
20 Fiesinger. I'm a family physician in Houston,
21 Texas, currently residency faculty. But as I
22 think of my experiences, I have worked in real

1 health screening clinics, I've been in large
2 multi-specialty groups, done QI, been medical
3 director of the FQHC.

4 Have also been a patient. You'll
5 hear about my six months, where three of the
6 four members of my family were in the hospital
7 within a six month period for surgery. My
8 first health care experience was going to
9 visit my mother in the hospital when she had
10 cancer as a teenager.

11 So I'm trying to think of this from
12 different perspectives. I'm curious to hear
13 what all the non-physicians have to say,
14 because we as doctors talk about this stuff
15 constantly. In family medicine, the patient-
16 centered medical homes are a big vehicle.
17 This is the wagon we've hitched ourselves to
18 to transform our specialty.

19 It's not patient-centered, dirty
20 little secret, and I'm in a Level 3 PCMH. We
21 spent a huge amount of time and effort to
22 become one, and we're not there yet. We're

1 hindered in frustrating ways by our own
2 biases, misconceptions, learned behaviors, and
3 it's been frustratingly challenging to take a
4 bunch of really innovative, open-minded people
5 and get them to change.

6 So I look forward to hearing the
7 insight from everyone else, and then a final
8 comment too. I think of diversity. I've got
9 retired engineer patients who bring in
10 spreadsheets, and ask me why there's so much
11 variation and statistical noise in their blood
12 sugars.

13 True conversation, and that's
14 challenged me to be a more attentive physician
15 at the same time, within the most diverse
16 county in our state. We have so many
17 languages. I have people who want lots of
18 information. I have demented patients who say
19 stop telling me all the numbers; just tell me
20 if I'm okay. Your letter is two pages too
21 long.

22 So how do I merge all that stuff

1 together? So you are going to tell me the
2 answers, right?

3 (Laughter.)

4 MEMBER FRANK: Good morning. I'm
5 Lori Frank with the Patient-Centered Outcomes
6 Research Institute, and I'm very happy to be
7 here, looking forward to learning from all of
8 you. You asked us to comment on our views on
9 receiving, delivering and measuring person-
10 and family-centered care.

11 So I'm all in favor of receipt and
12 delivery of person-centered care for sure. At
13 PCORI, we focus on the inclusion of patients
14 and other stakeholders in the production of
15 the evidence, and my particular interest is on
16 the measurement piece. My background's health
17 services research.

18 I'm a patient-reported outcomes
19 measures researcher, and interested in hearing
20 today about the hallmarks of a patient-
21 centered perspective. Thank you.

22 MEMBER JHINGRAN: Hi. This is --

1 I'm Priti Jhingran. I work for
2 GlaxoSmithKline, have been with the company
3 for 21 years now. My background is in health
4 outcomes. So my essentially academic training
5 is on measurement of patient-reported
6 outcomes.

7 In fact, the first year when I
8 joined Glaxo, my supervisor then essentially
9 made me do factor analysis and psychometric
10 analyses day-in and day-out, and I was like I
11 will never do patient-reported outcomes in my
12 life. That's how bored I was doing all that
13 stuff.

14 So yes, you know, I love that aspect
15 of developing measures which help patients and
16 really bring their perspective into research,
17 whether it's research being conducted by
18 pharmaceutical companies or outside.

19 My interest in this committee was
20 primarily because for about almost 15 years,
21 I was very inward-focused. I focused on
22 patient-reported outcomes, quality of life

1 measures which were needed for pharmaceutical
2 companies and for our research programs.

3 But after that, I stepped out and
4 actually went to the field, and that led me to
5 interact with customers. So people like
6 yourself, folks, executives in C suites who
7 are making decisions at a population level.
8 That just opened up my eyes in terms of what
9 the value of these kind of measures could
10 potentially be in providing health care to
11 patients, and what impact that can make.

12 So this is of great interest to me,
13 and I hope that I can contribute effectively.

14 MEMBER MAKAR: Hi. I'm Ellen Makar,
15 and I work at ONC. I'm a registered nurse.
16 Specifically, I'm in the Office of Consumer
17 eHealth. I left bedside nursing many years
18 ago because it was not congruent with my
19 values and how I wanted to deliver care.

20 When I decided to do that, I really
21 wanted to make a difference. I was in managed
22 care for a while, during a time when people

1 felt that managed care was the devil.

2 But there's a lot of us who were
3 nurses and patient advocates at the time, and
4 we were able to make a very big difference in
5 the way plans were thought of and patients and
6 customers were thought of. So that was a very
7 rewarding time of my career.

8 When I went back to the hospital, I
9 was surprised at how much hadn't changed. But
10 this time I went back as a leader and as an
11 administrator, and one who worked in quality
12 improvement.

13 Then I decided to come to
14 Washington. So I've been here for about a
15 year, working in consumer eHealth. I think if
16 we center on the consumer or on the patient,
17 we who are in the know can make sure that we
18 get to a certain degree patient-centered care.

19 All those who are not in the know I
20 think have much more difficulty, and even us
21 at times, who think we know things or have
22 connections, can't really seem to get it. So

1 that's my background and why I'm passionate
2 about this work.

3 MEMBER KENNEDY: Hello. I'm Cille
4 Kennedy. I apologize for being late. I work
5 for the Office of the Assistant Secretary for
6 Planning and Evaluation, and it's my role to
7 oversee the contract that is dealing with all
8 --

9 I don't know how much background you
10 got, so please forgive me for what I repeat,
11 and/or for what I assume that you know and
12 don't, because you haven't been told.

13 But anyhow, the five topics that are
14 filling the gaps in quality measures, and this
15 particular activity project on patient and
16 person-centered care and outcomes is work
17 that's in actually the vanguard. As much as
18 many of us have been imbued with that
19 philosophy, like well duh.

20 You know, we're all patients at one
21 point and we're all family at one point of
22 somebody else who is a patient, and it's just

1 common sense. There are many areas of the
2 world that don't quite see things that way.

3 So we're kind of breaking new water,
4 and you know, that's a kind of mixed metaphor,
5 in the work that's being done. But it's
6 valuable work. It's integral to -- I mean
7 just integral to the future of health care.

8 I also want to say that the job of
9 filling in the gaps that the five different
10 projects are working on, is something that
11 actually is derived from mandated law. So
12 it's not just vanguard work that's a popular
13 topic de jure, but something that grows out
14 of, you know, Congressional action.

15 So it's very important work that is
16 work that's going to stay. So you are the
17 experts who are also mandated by law; not
18 personally, but that will be up to Snowden,
19 not to me to say, but who come in and give,
20 you know, your expert wisdom to the
21 government. Because although we love talking
22 to ourselves, we really like to hear from the

1 real world and we appreciate your input.

2 Thank you.

3 MEMBER FORREST: Good morning. I'm
4 Chris Forrest. I'm a pediatrician and a
5 health services researcher at University of
6 Pennsylvania School of Medicine and Wharton
7 School of Business.

8 I'm on a research program that is
9 focused on building a pediatric patient-
10 centered research agenda. It's actually
11 housed in a center at Children's Hospital of
12 Philadelphia.

13 We have three dimensions to our
14 center. The first is creating new measures.
15 Our group has developed over 50 child- and
16 parent-reported measures of outcome, using
17 both modern measurement and classical test
18 theory. I also chair the NIH's PROMIS
19 executive committee, and help to catalyze the
20 development of patient-reported outcomes
21 across the country.

22 The second dimension is on family

1 partners. We have a very big family partners
2 program, trying to create resources for
3 families, for youth, for clinicians, to enable
4 research to be done in a co-participatory way.
5 Then we have a national network called PEDSNet
6 that I run.

7 It's funded by PCORI. It's one of
8 their CDRNs, that's putting patients and
9 families in the middle of a national research
10 network that's going to be sharing data and
11 conducting clinical trials.

12 MEMBER LEFF: Good morning. I'm
13 Bruce Leff. I'm a geriatrician and health
14 services researcher at Johns Hopkins. This is
15 the Johns Hopkins corner. Chris is formerly
16 of Hopkins, so this is the little ghetto of
17 Hopkins.

18 I'm very interested -- a lot of my
19 research has been on the development,
20 evaluation and dissemination of innovative
21 models of care for older people, hospital at
22 home, guided care, some others.

1 I also have a lot of interest in the
2 care of people with multiple chronic
3 conditions and have worked with NQF on
4 thinking about performance measurement for
5 that population. I'm doing a lot of work now
6 on developing metrics and a national registry
7 to inform quality-based improvement for home-
8 bound older adults. So medically homebound,
9 who really have no quality framework of it in
10 at all.

11 As a clinician, I'm very interested
12 in this, because I think that we can talk for
13 as long as we want to talk about person
14 centeredness. But systems matter a lot. So
15 I work at a wonderful institution, and I will
16 tell you that with all due respect to my ONC
17 colleagues, meaningful use has tortured us,
18 and has created -- and because of the
19 implementation aspects of it, has actually, I
20 think, caused a decrease in the quality of
21 care we provide.

22 I think the other piece is thinking

1 about how to modulate all of these various
2 constructs. Some patients want no
3 information. Some patients will never be able
4 to get online to get a single piece of data,
5 and how do you bring all of that to the fore.

6 So I'm really interested in seeing
7 how do you modulate, because person-
8 centeredness, not everyone wants that, you
9 know. Not everyone wants it. Some people
10 just want to be told doc, tell me what to do,
11 and even when we want to do that, sometimes
12 it's really hard to just do that. So I'll
13 stop kvetching.

14 MEMBER WOLFF: So I'm Jennifer
15 Wolff. I'm also at Johns Hopkins University.
16 I'm a faculty member in the School of Public
17 Health, in the Department of Health Policy and
18 Management, and I'm a health services
19 researcher. I collaborate quite a bit with
20 Bruce and colleagues in geriatric medicine.

21 My work has focused on health care
22 delivery for older adults with complex health

1 needs, and who often rely on a family member
2 to navigate the health system, and thinking
3 about the patient who may be homebound or may
4 not want to be involved in decision-making.
5 Oftentimes, they delegate decisions to a
6 family member.

7 So and for -- in some cases, family
8 members really are the backbone of health care
9 delivery and are integral to high quality
10 care, but sometimes they are -- their
11 involvement may detract from quality of care.

12 So I'm really delighted to be here.
13 I'm through a fellowship with ONC, working
14 with Kevin and with Ellen, where I've been
15 very interested in trying to understand better
16 the potential of health information technology
17 to facilitate family members' involvement in
18 patient care.

19 I'm really delighted that this
20 committee has decided to think about patient-
21 and family-centered care, and to take on the
22 challenge of thinking about when family

1 engagement may be different than patient
2 engagement, and thinking about the potential
3 of improving quality of care by better
4 preparing family members for their
5 involvement.

6 Also in supporting family care
7 givers with the education that they need and
8 the services that they need, so that they can
9 continue to provide care that is consistent
10 with patient -- with high quality care and
11 with patient preferences. So thank you.

12 MEMBER MACDONALD: Good morning. My
13 name is Mary McDonald. I'm not from Hopkins,
14 but I live in Baltimore in fact. I'm the
15 Director of the Health Care Division of the
16 American Federation of Teachers. We're a
17 union that represents 1.5 million
18 consumers of health care. We also represent
19 100,000 providers of health care.

20 Our interest -- and I'm also chair
21 of the Consumer Council for NQF. Our interest
22 is in developing tools that would strengthen

1 the patient's voice in the redesign of the
2 health care system. There are a lot of very
3 powerful institutional actors, who are
4 weighing in on what the health care system
5 should look like, providers, insurers.

6 Patients generally aren't among the
7 more powerful voices, perhaps because we're
8 not particularly well-organized. So I'm very
9 interested in developing tools to strengthen
10 that voice.

11 On other thing. I'm interested in
12 developing tools that are real too. It was
13 interesting what Troy said about patient-
14 centered medical homes. I'm a member -- you
15 know, I get my primary care from a patient-
16 centered medical care. There's a NCQA
17 certificate on the wall that says it. But it
18 certainly doesn't feel like patient-centered
19 medical home.

20 So I'm interested in developing
21 tools that actually make it real. Thank you.

22 MEMBER LEPORE: Good morning. My

1 name's Michael Lepore, and I currently work
2 with Planetree and adjunct assistant professor
3 with Brown University, in their Public Health
4 program. Planetree is an international
5 network of health care providers that are
6 committed to implementing patient-centered
7 care.

8 They've been around since the late
9 70's, and so have been able to see some of
10 this vanguard work. While I'm a sociologist
11 by training with some health services research
12 experience, I'm particularly interested in
13 experiencing the implementation and
14 operationalization of person-centered care
15 across long term care and acute care setting.
16 I'm foraying into home care as well.

17 So I'm excited for the measurement
18 aspects of bringing that to life. I'm really
19 a mixed methods researcher, so to the extent
20 that we're able to integrate both qualitative
21 and quantitative perspectives I think is
22 extremely valuable.

1 MEMBER CONNOR: Good morning,
2 everyone. I also am not from Hopkins, but my
3 daughter will be starting her residency there
4 in June. My name is Maureen Connor, and I'm
5 here representing the Institute for Patient
6 and Family-Centered Care today, on behalf of
7 Mary Minitti, who was unable to attend.

8 The Institute, as I'm sure many of
9 you know, works with health care organizations
10 across all settings, in helping to advance the
11 understanding and practice of patient- and
12 family-centered care. I had the privilege of
13 teaching in one of their seminars last week,
14 which was as usual an incredible experience,
15 bringing together over 400 attendees from all
16 over North America.

17 So in terms of my background, I'm a
18 nurse and I have extensive experience in
19 working with patients and families from the
20 Dana Farber Cancer Institute in Boston. I was
21 formerly the VP for Quality Improvement and
22 Risk Management there.

1 Although I would not consider myself
2 to be a researcher by any means, I have been
3 a co-investigator of two studies which have
4 involved patients and families, one of which
5 related to oral chemotherapy, so that we could
6 have in place mechanisms to ensure the safety
7 of that therapy.

8 Lastly, I come to this work as the
9 parent of a daughter with a chronic illness.
10 Thank you.

11 MEMBER EAMES HUFF: Good morning.
12 I'm Jennifer Eames Huff. I am Director of the
13 Consumer Purchaser Alliance, which is a group
14 of over 50 consumer, labor and employer
15 organizations that work together to advocate
16 for performance measurement and its use for
17 payment, public reporting and quality
18 improvement.

19 So I think at the heart of the work
20 that we do is really to be patient- and
21 family-centered. That's really important and
22 the core of our advocacy work, and how it

1 plays out in measurement and being patient-
2 and family-centered.

3 I'm also housed in the Pacific
4 Business Group on Heath, where I am the
5 Director of Advancing Policy. PBGH is an
6 employer coalition, with over 50 large self-
7 insured employers. PBGH also has an interest
8 and has been doing a lot in the area of
9 patient- and family-centered care.

10 A couple of projects. We've
11 launched the California Joint Replacement
12 Registry, where we're working on doing hip and
13 knee replacement joint registry, and
14 incorporated patient-reported outcomes into
15 that registry.

16 Another example is we have started
17 an Employer's Center of Excellence Network for
18 hip and knee replacement as well, and again to
19 be a member of that center of excellence, you
20 have to have the use of patient-reported and
21 outcomes of care.

22 I think on another note, some of my

1 history started way back, if you can believe
2 that, when I used to work at the Picker
3 Institute, which was really the tag line was
4 "Through the patient eyes," and really seeing
5 health care through the patient eyes.

6 So I've had a long history of really
7 having patients at the heart of health care.
8 Thank you.

9 MEMBER NYMAN: Good morning. I'm
10 Mark Nyman. I'm a general internist at Mayo
11 Clinic, and I chair a group and we're the
12 Patient Profile Subcommittee, and we're tasked
13 with collecting, electronically collecting
14 information from patients, clinically relevant
15 information, including patient-reported
16 outcomes, and interested in how to optimize
17 the connection between that information and
18 the health care team.

19 I also have been involved with
20 Minnesota Community Measurement, with public
21 reporting and creating public reported
22 metrics. Thanks.

1 MEMBER WALLING: Hi. My name's
2 Annie Walling. I am a palliative care
3 physician and a health services researcher at
4 UCLA. My research is really focused on
5 quality measurement and improvement. The
6 measures that I've been involved with the most
7 are process measures for supportive care,
8 really focusing on patients with serious
9 illness.

10 The reason I am so passionate about
11 this topic in particular, though, I think
12 really stems from a early personal experience,
13 when my mother had traumatic brain injury in
14 her 30's, and really the experience that me
15 and my family had during that period of time,
16 really I think influenced the way I
17 experienced my medical training, and I really
18 was able to see care through the eyes of the
19 patient, as well as the physician.

20 So I feel that this is a really
21 important topic, and I'm really excited to be
22 here.

1 MEMBER GHAZINOUR: Good morning.
2 This is Mitra Ghazinour, and I'm a project
3 manager at NQF. I'm sure all of you have been
4 receiving so many emails from me. Thank you
5 so much for your patience. Thank you so much
6 for all your contributions.

7 I'm supporting this project, as well
8 as other projects at NQF, including one called
9 MAP, Person- and Family-Centered Care. I'm so
10 thankful that all of you could join us today.
11 I believe we have one committee member online,
12 Lisa Latts. Lisa, would you like to introduce
13 yourself?

14 MEMBER LATTS: I would, thank you,
15 and I apologize to everybody for not being
16 there. I had intended to be there. You know
17 what happens to best-laid plans. So thank you
18 very much.

19 So I'm Lisa Latts. I am influenced
20 by training with subspecialty in high risk
21 pregnancy care. But my background is in the
22 payor world. I worked for WellPoint for many

1 years, focusing on quality improvement,
2 quality measurement, patient safety, as well
3 as delivery system transformation and how do
4 we do quality from an innovative perspective,
5 looking at how we change the delivery system,
6 and as well as have spent a little bit -- too
7 much time as a patient over the past few
8 years. So I have a perspective there as well.

9 My interest, as it relates to
10 person-centered care, is the inevitable
11 conflict that I see arising in the future, as
12 person-centered care becomes more of a thing,
13 between that and quality measurement and
14 accountability, particularly as we look
15 towards more of a value-centered health care
16 system and what that means from a system
17 perspective, a physician perspective, patient-
18 centered, person-centered perspective, and I
19 see some potential clashes occurring there.

20 So I think that's something I just
21 want to make sure is thought through. So I
22 will hopefully be able to do as much as I can

1 on the phone today. So thank you.

2 MS. PACE: All right. Thank you
3 everyone, and I'm Karen Pace, the senior
4 director for this project, and again join
5 Mitra in thanking you for offering your time
6 and expertise to this project. So I think
7 with that, we will move on to our next agenda
8 item, which we've asked our co-chairs, Sally
9 and Uma, to just kind of do a little setting
10 of the stage for our work, and we'll turn it
11 over to them.

12 Setting the Stage

13 CO-CHAIR OKUN: Great. Well, it was
14 really so wonderful to hear everyone's
15 background, and to get a sense of just the
16 scope of the expertise in the room. One of
17 the things that struck me particularly was the
18 range of experiences across settings, and I
19 think that's something that we've actually
20 tried to pay attention to.

21 Certainly, my background has been
22 community care and community-based care for

1 most of my career, and I think it is
2 marginalized often when we think about how to
3 do we measure that and good quality care
4 there, and I think we'll identify certain
5 numbers of gaps that we can probably think
6 about filling.

7 If you'd move to the next slide,
8 that would be great. I don't have control, do
9 I?

10 FEMALE PARTICIPANT: No.

11 CO-CHAIR OKUN: Okay. I don't like
12 not having control. I'm teasing. So our
13 charge this morning is to just give you a bit
14 of an overview, and set the stage for what the
15 next few hours today will be like, and then
16 what we're hoping to accomplish tomorrow. So
17 this first slide really just goes over the
18 three key points in our objectives for today,
19 and that will be to finalize, to the degree
20 that we can agree, the definition and core
21 concepts of what ideal person- and family-
22 centered care looks like, what is it and where

1 we feel we'd like to put a stake in the ground
2 on that.

3 How to identify the measure for
4 person- and family-centered care. If we look
5 at each of the core concepts, we really have
6 to test our assumptions. Can it be measured?
7 Is there a way for us to meaningfully gather
8 data on this and then hold someone accountable
9 for it?

10 But at the same time, what I did
11 hear as everyone went around, which really was
12 quite interesting, many of you have a personal
13 story. So apply that lens on it as you're
14 looking at it. Each of us has our own
15 experiences with the health care system in our
16 own delivery systems, and I think, you know,
17 your experience in the patient-centered
18 medical home is really interesting.

19 You know, we're sort of told that
20 these things are coming or they're there, and
21 yet we may not be seeing them. So if we're
22 not seeing them and we're not aware of them,

1 or if we have a family story that's helping us
2 to illuminate where those gaps are, that
3 insight is really going to be helpful here
4 today, and then prioritize opportunities for
5 person-centered care, performance measurement
6 over the short and longer term. So I think we
7 can't solve everything here in these next two
8 days.

9 But what we're trying to do is set
10 the stage for where things can go, and what
11 can ideal look like if we have that vision
12 set, but have it be a realistic idealism, so
13 that we actually can achieve it at some point.

14 So I'm just going to go briefly
15 through the agenda for the day. It's actually
16 pretty busy, so we've already done a few
17 things. But we're going to get a project
18 overview, and that's going to help us get a
19 better sense of the related NQF projects,
20 because one of the things that I think many of
21 you may be feeling, as you go over the
22 documents that we've already had available to

1 us, there's so much happening.

2 Then if you look in your own
3 backyards, you know there's a lot happening in
4 yours too. So what we want to do is really
5 get a sense of how things are connected, how
6 can we contribute something unique and new,
7 but also provide some opportunities for others
8 to look to us to say well this is the way they
9 look at it, and maybe we need to start
10 thinking about that lens.

11 So we'll have an opportunity to
12 really hear some of that, and then go again
13 deeply into the definition and the core
14 concepts, really spend some additional time on
15 that.

16 We'll have an opportunity for public
17 comment this afternoon, and then we're going
18 to actually have some time to spend with each
19 other, really thinking through the core
20 concepts, and starting to put some real hard
21 challenges to them, to suggest whether or not
22 these are things that we can actually start to

1 identify ways of being able to measure first,
2 and then measure the performance against.

3 So and then ultimately we'll have
4 the report out at the end of the day on that.
5 So the next slide. Tomorrow, we'll be
6 starting fresh again hopefully, after having
7 spent most of today really getting to know not
8 only all of the issues and challenges ahead of
9 us, but also getting to know each other.

10 Because I think that's where
11 actually a lot of the work really starts to
12 get enriched, when each of us is bringing a
13 perspective that the other might not have, or
14 it helps illuminate a perspective I have, but
15 maybe I needed to see it through a different
16 perspective. So that's really important to
17 me.

18 We'll have again some more
19 opportunity for public comment, and then
20 ultimately break down into some small groups
21 again, and really try to bring back to the NQF
22 some meaningful content for them to take then

1 to the next step. You can go on to the next
2 one. I think that's fine.

3 So what I think is most important is
4 for us to set some expectations for the work
5 that we're going to do here today. Really, I
6 think we've already learned a lot about each
7 other.

8 It's really always nice to start
9 that way, because a lot of what we're going to
10 do today is going to challenge assumptions.
11 We're going to have to start testing how we're
12 thinking about certain things, and there are
13 going to be times where we may not agree.

14 I think that the environment of safe
15 discussion and respect for each other's
16 opinions, and really feeling okay about being
17 able to say you know what? I could live with
18 that. I'm not necessarily liking it as much
19 as I would hope, but I can live with it. I
20 think that's an opportunity for us to
21 demonstrate just how challenging it's going to
22 be even to roll these out beyond this group.

1 So having a sense of where we see
2 tension, where we see challenge. If we bring
3 those to the surface as a group, I think that
4 will help us be able to better understand what
5 challenges may lay ahead if we put this out as
6 a shorter or longer term objective.

7 So really helping to move towards
8 consensus is really our objective with this.
9 Not necessarily to get perfection, but to get
10 to a point where it's really good enough to
11 feel like we've put a lot of work into
12 something that we can now give to NQF and to
13 HHS and ONC, to say okay, this is -- the body
14 of this is great. We're going to now really
15 start to do some hard work on it.

16 We have to meet our objectives, and
17 we also have to stay on time. So I'm looking
18 at the time now, and I'm going to finish up
19 quickly.

20 The next slide please. So the scope
21 of this project, as many of you will recall,
22 when we started this, when the landscape was

1 laid out for us early in this by Mitra and
2 Karen, it was really sort of taking an
3 opportunity to look at the domains of quality
4 that IOM had laid out, as well as the National
5 Quality Strategy priorities.

6 Each of those actually have a very
7 high definite focus on patient-centeredness.
8 So part of this is not just coming out of the
9 blue, as you all know. We're working on
10 something that is being worked on across
11 numbers of domains around the country, and
12 globally actually.

13 I remember I came from a meeting in
14 the last couple of days, very much focused on
15 engaging patients, families and communities in
16 inter-professional education.

17 One of the things that I think was
18 really interesting to me, and Uma might
19 comment on it at some point later, is that on
20 the Montreal model for this inter-professional
21 education, they actually moved from having the
22 patients in the center to having the patients

1 as part of the whole circle, so that everyone
2 is sort of part of the same team.

3 I've often thought that that was a
4 better way than actually the centeredness
5 piece of it. But it's really a change in the
6 way you think about them. When you add them
7 fully as team members or partners, you almost
8 have to shift it slightly in the way that
9 we've been thinking about.

10 So again, just a new challenge, a
11 new way of thinking, a new lens to look
12 through, a new opportunity for us to have some
13 fun as well as some intellectual discussion
14 about all of this. So thank you.

15 CO-CHAIR KOTAGAL: Thank you, Sally.
16 It is true I had never met Sally until four
17 days, and we have spent the last four days
18 together.

19 CO-CHAIR OKUN: We know each other
20 well.

21 CO-CHAIR KOTAGAL: And have come to
22 know each other well. I, like Sally, was

1 stuck by the passion and the personal stories
2 that have brought each of us here, and I know
3 in the call, we experienced a lot of that
4 passion and attention to detail and so on.

5 So as we move forward, Sally's
6 challenge about how we get to consensus and
7 how we stay on time will be an interesting
8 opportunity, I believe, for all of us.

9 Now I want to just clarify the term
10 "measurement." If you said you're measurement
11 experts, so obviously this is a little bit
12 redundant for you. But just to remind you
13 that when we're thinking about the patient
14 level outcomes, we're really thinking about
15 individual items that reflect an individual
16 patient's view, whether it be blood pressure
17 or lab values or an instrument or a scale.

18 But when we're thinking about the
19 organization level measures, we're thinking
20 about something rolled out, aggregated. That
21 helps us think about the measurement. I think
22 when we begin to think about measuring

1 patient- and family-centered care, the patient
2 reported outcomes become really important, and
3 the prior work of the NQF on patient-reported
4 outcomes and performance, has used this
5 definition of the patient-reported outcomes as
6 any report on the status of the patient or a
7 person's health condition, health behavior,
8 experience with health care that comes
9 directly from the patient without
10 interpretation, filtering of this by somebody
11 else, that says "No, I think is really what
12 they meant, even though they didn't say it,"
13 that sort of modification.

14 The three domains that I think we're
15 interested in, as we think about this -- the
16 four domains, the first is obviously the
17 health-related quality of life or the
18 functional status; the symptoms and symptom
19 burden, pain, fatigue, experience with care
20 specifically, communication, decision-making,
21 which is what we're focused on a lot, and then
22 health behaviors and how the patient reports

1 and thinks about their interpretation of it.

2 Now measuring this is reflected in
3 the core concepts, is often described and
4 usually measured as a survey using tools and
5 instruments that many of you are obviously
6 familiar with, and maybe helpful as many of us
7 think about our perspective of improving this,
8 taking this back to the delivery system and
9 thinking about whether we've made any
10 progress. Has the patient reflected this a
11 little bit differently?

12 And the various tools may be used
13 when delivering patient-centered care, if
14 they're used actively by the patient to
15 identify goals and to manage their care. So
16 not just as a measurement of progress, but
17 also how does the patient use that
18 information, and how do we use that
19 information to make a difference. So I think
20 that that's very, very important.

21 If we get to the next slide, I think
22 our task is to identify, you know, the

1 measurement framework and the task more
2 clearly this afternoon, but a couple of
3 comments for us to think about, as we think
4 about definition and core concepts.

5 These are kind of important, because
6 they will serve as our starting point, the
7 classic areas that we think about in terms of
8 structure, process and outcome.

9 We think about the core concepts
10 that we have been working on for some time,
11 and there are various structures and processes
12 that are important, that can be used to
13 support the organization, the patient who
14 received the care that we think they need to
15 receive.

16 So we think about the experience of
17 the patient and think about outcomes. We also
18 think about the structure that results in the
19 delivery or the processes of care that
20 deliver, result in delivery of the outcomes.

21 So as we think about this, the task
22 that we'll be thinking about really tomorrow

1 is, you know, we'll hear more about this. But
2 here are a few questions I wanted to sort of
3 leave you with as we're thinking about this.

4 What information would be meaningful
5 to consumers? What is relevant across
6 settings, across time and across programs, and
7 finally, what should be really measured from
8 the patient point of view? So I think what
9 that in mind, I'll turn it over to you.

10 MS. PACE: Okay, thank you. So
11 we'll have lots of things to talk about today,
12 and hear from others, and we're going to go
13 ahead and hear from Kevin Larsen, who will
14 give us the kind of background on why this
15 project was funded.

16 Project Overview and Related NQF Projects

17 MEMBER LARSEN: Yes. Thank you so
18 much. As we mentioned, this is part of a
19 Department of Health and Human Services
20 overall project, looking at gaps in
21 measurement. So many of you are aware of the
22 National Quality Strategy. The National

1 Quality Strategy is the federal strategy for
2 how, what should we doing about quality in
3 health care, and as we worked across HHS to
4 improve on the -- improve towards the goals of
5 the National Quality Strategy, we noticed that
6 many of the areas that we prioritize as a
7 country we don't actually have good measures
8 in.

9 One of those key places is in person
10 and family-centered care. So this is funded
11 really specifically to give input to the
12 federal government, to say hey, if we're going
13 to investing money, which we will be in
14 additional measure development for person- and
15 family-centered care, here is where we should
16 be investing that money.

17 These are the -- this is the
18 framework, these are the opportunities, this
19 is the way that it should work. So we're
20 really hoping and looking to this group to
21 help us build out what that investment plan
22 would be, for the kinds of measures we want as

1 part of federal programs.

2 Certainly, we're hoping that this
3 has a broader impact beyond just that, that
4 others of you in other places, in other parts
5 of the country, can also use this work. It's
6 all free and open to whoever would use it.
7 But it was specifically funded for that
8 particular purpose.

9 We're really excited that we have
10 not just health care people, but we have a lot
11 of people that are here as experts of
12 consumers and engagement in how these work in
13 people's lives and in communities, and in
14 purchasing. It is real easy for us to get
15 focused and internally navel-gazing as health
16 care people.

17 So we look to the rest of you to
18 keep us honest, and tell us when we're using
19 terms that aren't -- you don't understand are
20 that are insidery, and we also really -- help
21 us to be open and thoughtful to the new ideas
22 and the things that really make sense, because

1 again we come with a long legacy of
2 internalism, and we want very explicitly here
3 to not -- to not have this look like
4 everything else.

5 I think there is -- as we've kind of
6 mentioned, there's an easy path that we just
7 say patient-reported outcomes are person-
8 centered, person- and family-centered care,
9 and I think that patient-reported outcomes are
10 really a key building block.

11 However, this has been more than
12 that. So I want to make sure that we're
13 thinking broadly enough, that this isn't just
14 what's the next group of PROs that we use in
15 the government.

16 A little bit of more personal
17 stories, kind of how did I get to this place.
18 Many of you have heard me talk about my
19 brother. I've got a brother who I'm very
20 close to, who's a Type 1 diabetic. So he was
21 diagnosed with diabetes when he was seven and
22 I was nine.

1 Little did I realize that I got to
2 experience fantastic patient- and family-
3 centered care from the time I was nine. So if
4 any of you are familiar with the International
5 Diabetes Center in Minneapolis, it was started
6 in the 70's by a really terrific pediatrician,
7 and it was multi-disciplinary, and the whole
8 family went.

9 So we used to go for day-long
10 visits, where all of the providers were
11 organized around us. We got to have dietary
12 and education sessions for the family; we had
13 the doctors were there, the nurses were there
14 with the exercise trainers, with everybody we
15 could think of.

16 We would go a couple of times a
17 year, and then sometimes we'd go for a week
18 for classes as a whole family to this
19 education session, to help us learn as a
20 family how to support my brother with his
21 diabetes.

22 I got into health care as a

1 physician and I'm like wait, the rest of the
2 health care system isn't like this. This is
3 how care is supposed to be, and I'm not seeing
4 this in the rest of health care.

5 Why isn't the rest of health care
6 like this? So I think I was very lucky and
7 really looked to the kind of leadership of
8 that group for many, many years and how they
9 thought about it.

10 I also think that having a kind of
11 deep connection to Type 1 diabetes has helped
12 me understand this as well. Type 1 diabetes,
13 when my brother was diagnosed, was a condition
14 where you managed your life around your
15 diabetes. So you got a shot of insulin, and
16 your whole day was prescribed.

17 When my brother was seven, he had a
18 set of measuring cups that he had measure all
19 of his food and there was a scale next to his
20 plate, and we had time all of our meals when
21 exactly we would have them, and we would
22 measure the food by how much it was. He

1 couldn't have more or less than that. My job
2 as his brother was to keep track of all this,
3 and we never would dare change any of this
4 without calling the doctor.

5 In the early to mid-80's, this made
6 a radical shift, and the diabetes world said,
7 you know, we need to give diabetics control of
8 their own treatment and their own ability to
9 change things. It made a radical fundamental
10 shift, to where now the patient was in charge.

11 They called the shots. They knew
12 their body better than the doctor did. They
13 were allowed to make all their own
14 adjustments, and all of a sudden you started
15 managing your diabetes around your life. It
16 was remarkable and ground-breaking, and again
17 15 or 20 years ahead of where we are with a
18 lot of other conditions.

19 They made a very conscious effort,
20 it's something I've been following as a
21 physician, that I'll meet with patient
22 educators. So previously I was a hospital

1 administrator. I would meet with and study a
2 lot of health literacy, and I always would go
3 for the diabetes educators, because everybody
4 else still had this notion that what our job
5 was was to spoon feed patients in exactly how
6 to do things.

7 The diabetes educators had a whole
8 model for how do I help people understand
9 enough about what's going on, so they have a
10 wide range of options and they can be in
11 charge of their own life.

12 So I hope that we have, as an
13 outcome of this, can find ways to measure what
14 the difference is between that diabetes center
15 that we went to when I was a kid, and the kind
16 of clinics I worked in my whole life that
17 weren't like that, and how could I help guide
18 people to get to the place that is going to
19 best meet their needs.

20 MS. PACE: All right, thanks. Mitra
21 is going to tell us a little bit, just a quick
22 overview of the projects, since you've heard

1 that, and then some things about related NQF
2 projects.

3 MEMBER GHAZINOUR: Thank you, Karen.
4 So I'm going to provide a brief summary of the
5 activities that the committee has undertaken
6 to date, and also talking about the next steps
7 and related NQF projects.

8 So back in October, a few committee
9 members, as part of the initial advisory
10 group, participated in a web meeting to
11 discuss the goals for this project, and also
12 to discuss the approach to achieving those
13 goals.

14 So the goals that we have today in
15 front of us include envisioning that ideal
16 person- and family-centered care, and use it
17 as a framework to measure, to develop
18 performance measures, and also to provide
19 short term and longer term recommendations on
20 how to measure and develop measures.

21 So once the whole committee was
22 formed in January, the committee again

1 convened at that meeting, and we presented the
2 draft, the finished core concepts that were
3 based on the foundational works of the NQF
4 priorities, as Uma and Sally alluded to, and
5 after the web meeting, again we conducted a
6 survey to further refine those core concepts
7 and definitions, and also receiving additional
8 input from the co-chairs.

9 We have the definition on core
10 concepts today to discuss even further, and
11 hopefully to gain consensus.

12 So moving on to the time line slide,
13 the next steps including the submission of the
14 draft report to HHS on June 16th, which will
15 include the recommendations that will be
16 emerging from today's discussion, and followed
17 by the public comment, a three week public
18 comment starting June 23rd through July 14th,
19 and again on June 30th, NQF will hold a public
20 webinar.

21 During that public webinar, the
22 recommendations from the three committees

1 under this project, care coordination,
2 workforce and person-centered care outcome.
3 We'll be reviewing the recommendations and
4 just pushing out information to the public,
5 and encouraging public to submit comments on
6 the draft report, via the commenting tool on
7 the NQF website. Lastly, the final report
8 will be due on August 15th.

9 Moving onto the next slide, so as
10 when Karen mentioned earlier, we have other
11 projects focusing on this concept at NQF. The
12 one in the green is our project, person-
13 centered care outcomes. The one on the top in
14 the orange box is called the MAP Person- and
15 Family-Centered Care Family of Measures, and
16 which I'm also supporting that project.

17 So basically NQF has been asked with
18 convening multi-stakeholder groups called
19 Measure Application Partnership, to provide
20 rulemaking input to HHS on quality measures
21 for public reporting and performance-based
22 programs and other purposes.

1 So one of the Measure Applications
2 Partnership or MAP task forces has been
3 charged with promoting person- and family-
4 centered care, by identifying a family of
5 measures. So what is a family of measures?
6 So the definition of a family of measures is
7 a set of related available measures and
8 measure gaps that span programs, populations,
9 a level of analysis and settings.

10 Up to date, MAP has identified
11 families of measures related to the NQF
12 priorities of care coordination, safety for
13 populations including eligible beneficiaries,
14 cancer, hospice, and in 2014 MAP it will be
15 identifying families of measures for
16 affordability, population health and person-
17 and family-centered care.

18 So the other project is the
19 endorsement project, and NQF and the
20 respective committee will be looking at
21 measures for endorsement to build NQF
22 portfolio in this area, person- and family-

1 centered care, and actually Karen Pace is
2 leading that effort.

3 So the last project is the Patient
4 and Family Engagement Action team, and also
5 Wendy is leading that project. As its name,
6 such as it's an action-oriented project, which
7 brings together 20 groups of health care
8 leaders to share resources, tools and best
9 practices to promote patient and family
10 engagement.

11 So at NQF, you're trying to
12 integrate all these recommendations from these
13 different committees, by sharing staff across
14 all these projects. I guess that concludes
15 this section. All right. Do you have any
16 questions?

17 CO-CHAIR OKUN: I suppose questions
18 on this and anything that's been brought up.
19 I think what we'd like to do is sort of before
20 we take the break, to see if there's any
21 burning questions or anything that's on
22 someone's mind that we, you know, really need

1 to get out and pay attention to, or that you
2 just want to say sort of setting the stage.

3 We can do that now. We break at
4 10:15, so we do have some time.

5 MEMBER deBRONKART: So I don't know
6 if I want to get myself kicked out of this
7 party or something, but because I don't have
8 umpty-years of expertise and experience in
9 this industry, I think about it from the
10 perspective, and I have immense respect for
11 all the things that people here know that I
12 don't have a clue about.

13 But I've got to say what to me is
14 the giant elephant in the room, is that this
15 is the only industry I've ever seen where
16 defining quality doesn't start by asking the
17 end user, the ultimate stakeholder, what's
18 important to you, okay.

19 Whatever we do, for all the micro-
20 measures, my view is that every single visit
21 ought to end with the simple question how was
22 this for you? Did you feel like you were

1 taken care of, right, and that that is like --
2 I mean if that isn't the ultimate patient-
3 reported outcome, I don't know what is.

4 I just visited my mother in
5 Annapolis this weekend, and they were having
6 way too much time in the waiting room. So now
7 within 15 minutes, she's put in an exam room
8 where she waits 45 minutes. Well, but we
9 know. This is the way -- you get what you
10 measure, right, and we know that from other
11 industries.

12 And one other thing regarding
13 systems and variation. Who was it that had
14 the patient that's an engineer? It was my
15 people. Well at the National Board of Medical
16 Examiners last week, at their annual meeting,
17 they gave an award to a woman named Robin
18 Tamblin, who has been working for years.

19 They produce the test that everyone
20 has to pass before they can be called an M.D.,
21 and this woman got this achievement award
22 because she's been working on whether the test

1 items in that exam correlate downstream with
2 how well the doctor actually does in practice.
3 She had this great diagram that I'm going to
4 try to get the slide, that said the course of
5 a disease, without treatment, is like this.

6 Somebody gets kidney cancer like me;
7 they go downhill, they die, all right. What
8 the public wants is say pretty close to
9 normal, right, and the actual, observed
10 variability goes from there all the way down
11 to worse than nothing.

12 So the question is what do we do to
13 bring that up, and there's -- I just
14 discovered there's a discipline called HRO,
15 High Reliability Organizing, that gets really
16 deep into that stuff. I know there are a lot
17 of heads here nodding about it, but most
18 people, hardly anybody I've talked to has ever
19 heard of it. So that's another asset which
20 will go into quality. But it's not the
21 patient-reported quality.

22 One final thing. Sometimes somebody

1 said "patient-centered." Well sometimes the
2 patient just wants you to decide. My personal
3 feeling is who gets the say on that, you know?
4 If the patient wants -- there were times when
5 I needed the doctor or nurse to say what we
6 were doing next.

7 So patient that to me, even if
8 somebody followed the discipline of "no, the
9 evidence says that things work out better if
10 you decide," I would mark that as no, this did
11 not work out well for me.

12 MEMBER JHINGRAN: I have a process-
13 related question. I guess the four
14 workstreams you talked about around patient-
15 and family-centered care, how did it all come
16 together? Because there is certainly some
17 overlap between the four. So I'm trying to
18 understand, and I'm assuming that these
19 workstreams kind of are going simultaneously.

20 So how do we pull it all together,
21 and is there any cross-fertilization between
22 the workstreams, to get a better sense of what

1 others are thinking relative to what this team
2 is?

3 MEMBER LARSEN: Sure. I'll take a
4 quick start. So many of these are generated
5 by Health and Human Services, and we ask NQF
6 for certain activities. So I would say that
7 some of them are in different stages in the
8 pipeline.

9 So if you think about the pipeline
10 as being development and then creation of
11 measures, and then measures ready for
12 government programs, there's a development
13 part of that.

14 One of these is in the -- are the
15 created measures the right measures, and then
16 the final one is are those measures mature
17 enough now to be in federal programs? So
18 there is definite overlap, you know, more on
19 the details of how NQF is doing it and the way
20 they're thinking of it.

21 But that's at least from the federal
22 side, who's asking for some of this work to be

1 done by NQF. That's part of the way we're
2 thinking about it.

3 MS. PRINS: Thanks Kevin. I'll just
4 add on to that process-wise. At NQF, I think
5 as Mitra was talking about, you heard that the
6 three of us, Mitra and Karen Pace and I are
7 all very involved in the projects. So staff-
8 wise, we're trying to make sure that we're
9 building when it makes sense. So for example,
10 on the MAP person- and family-centered care
11 family of measures, we are taking information
12 from this group and using it with that group
13 that will meet in May.

14 So we're really trying to use the
15 building blocks as we can. The time lines, of
16 course, make that challenging sometimes, and
17 those are pretty much when HHS needs
18 something, they need things. So we're doing
19 our best to make sure that we're collaborating
20 with them, but doing the necessary connections
21 within NQF, and also with certain committee
22 members.

1 MEMBER MAKAR: One thing that I just
2 want folks to keep in mind is some of the
3 unintended consequences.

4 After just having come off of a
5 large EMR implementation at a large academic
6 medical center, and having spent years really
7 working with core measures and some very
8 important work, quality work where it was
9 troubling to me that we really weren't
10 measuring anything, sometimes then what can
11 happen is something very good about the
12 clinician really wants, and wants to do for
13 patients, the way it becomes systematized
14 makes it very difficult to actually get that
15 end product.

16 So I just know one of my efforts is
17 to make sure that those that are at the sharp
18 end, especially clinicians who are caring for
19 patients, don't somehow get held accountable.
20 So when we say "held accountable," I just kind
21 of want to leave that out there as one of
22 those things to remember. That is a good

1 thing, but it can also have unintended
2 consequences.

3 MEMBER FORREST: So I want to make a
4 comment about the overall charge, which I see
5 we're fairly well-calibrated on. But I want
6 to throw in a new perspective, that maybe will
7 at least give you a sense of where I'm coming
8 from. That is, I really think we are focusing
9 on patient- and family-centered health care
10 services, not care.

11 So a quick story. I asked my 100
12 Wharton students who were taking my MBA course
13 on health system, to draw. I gave them a
14 blank piece of paper to draw their health
15 system. 80 percent of them put themselves in
16 the middle of the page, and drew their fitness
17 instructor over here, their yoga instructor
18 over there and around, there was a health care
19 provider over here.

20 I then took the Department of Health
21 Care Management faculty and gave them the same
22 exercise, and their ages ranged from about 35

1 to 80. They put their doctor in the middle,
2 and then they arranged the doctors, the health
3 care facilities around them.

4 I wondered if I asked my Wharton
5 students how they would define patient or
6 person-centered care, they might define it as
7 something like this.

8 It is an approach to health
9 management that involves health care providers
10 in the co-production of patient and population
11 knowledge and know-how, that enables us to
12 improve our outcomes that matter to us.

13 So what I'm arguing is that, you
14 know, working in I think is somewhat
15 anachronistic model of a provider-focused
16 system, that the scope of what we're doing is
17 really about the quality of the services
18 delivered in health care settings, but that's
19 not where health is produced.

20 So what's missing for me around this
21 is the connection to better outcomes, that
22 matter to me as patients, that matter to me as

1 family members. So if we're really wanting to
2 get to an operational set of measures, then
3 great. I think we're well along the way.
4 We're well-calibrated.

5 But we should also bear in mind that
6 maybe this is a minority view, that we're not
7 really describing person-focused care, care
8 that enables me as an individual to empower
9 myself to co-produce knowledge with people
10 that I bring into my system. It can be my
11 fitness instructor, it could be my primary
12 care doctor; it could even be a Johns Hopkins
13 doctor like Bruce Leff.

14 MEMBER LEFF: So Chris had some of
15 what I was going to say, but I'll go to a
16 different aspect of that. So we're going to
17 be exploring these core concepts, getting
18 towards measurement. I think in this sphere
19 especially, there are lots of things that
20 would be nice to measure.

21 There's probably a subset of those
22 that we can actually measure, and then I think

1 it's very, very important to think about the
2 subset of those that you can measure well,
3 that will actually have an influence on an
4 outcome.

5 So the linkage between the
6 measurement and the outcome should be very
7 tight, because otherwise we can create a lot
8 of stuff that's just going to send everyone
9 down rabbit holes, I think.

10 MEMBER FIESINGER: So I wanted to
11 speak as a consumer. I was present in my
12 state chapter of family physicians last year
13 and our state medical society. Physicians are
14 a conservative lot; a lot of us don't like
15 change. But a lot of us are very frustrated
16 as the consumers of these measures, and I'll
17 give a couple of examples. This ties into the
18 consequences.

19 Our health system probably as being
20 a high reliability organization, drives all
21 events to zero. CEOs at the hospitals are
22 rewarded or fired based on their performance

1 along those lines. Physicians, you know,
2 modify their behaviors.

3 In our residency, sort of we track
4 how long it takes to be able to respond. So
5 we track how long it takes to send out lab
6 results. One of the third years said "Okay
7 guys, here's the trick. Just sign off the lab
8 and leave it on your desktop and don't
9 respond."

10 So the patient never gets a letter,
11 but their data looks better. So we're going
12 to fix that problem; we're working on that
13 now. But I worry about those unintended
14 consequences.

15 There's a second anecdote. I was on
16 a Work Group for Hepatitis C Measures, and
17 there's the new recommendation. We check
18 every one born from 1940 to '70, I hope I'm
19 not getting the years wrong, for Hep C. I
20 said in my practice, the prevalence is fairly
21 low. I have other things I want to focus my
22 energy on.

1 I worry about the time burden and
2 the response from the medical director at the
3 University of Chicago was oh, it doesn't take
4 that much time. You can do it quickly. I
5 said no it doesn't, but our list is this long.

6 Third anecdote, you know, we're
7 going to publish our quality measures in two
8 months. When I see a diabetic, first thought
9 is treat the diabetic; second thought, my
10 denominator just went up by one, and when I
11 check my numbers tomorrow, no eye exam, no
12 microalbumin, no A1c until I get the numbers
13 back. If it's high, oh my out of control
14 measure, numerator just went up by one.

15 That's just honestly how I'm
16 thinking. That's tied to money, that's tied
17 to prestige. I believe wholeheartedly in
18 measuring, but I've got to triage what I do in
19 the 20 minutes I have in the office, and we
20 increase our appointments by five minutes to
21 deal with this stuff. We can't go up to 30.

22 So I think we always have to think

1 of the impacts on physicians, nurses, staff,
2 systems. There's a whole slew of unintended
3 consequences you alluded to, and you may get
4 what you measure, which may not be what you
5 want.

6 CO-CHAIR OKUN: So actually we're
7 getting close on time, so Joyce and then
8 Maureen.

9 MEMBER DUBOW: I just want to
10 respond to Chris' observation, and a little
11 bit to the last comment. Kevin gave us our
12 charge. He said that we -- that gaps in
13 measurement is the focus, and that we need to
14 identify where the government should spend its
15 resources. We can't -- I think we have to be
16 realistic about what the scope of this effort
17 is.

18 There are lots of places at NQF that
19 are dealing with measure burden, or as some
20 consumers and purchasers like to call it,
21 measure effort.

22 MEMBER FIESINGER: We say burden.

1 MEMBER DUBOW: Right, and so it
2 depends. Where you stand is where you sit or
3 whatever. But I think we need to be
4 realistic. I don't think anybody -- we should
5 not think that when we think about improving
6 health, that we think about the totality of
7 how people receive services.

8 But our function here is around
9 measurement and what the measures will be used
10 for, and we have a pretty good handle on what
11 the measures are going to be used for. We
12 know they're used for accountability, which
13 includes payment, public reporting.

14 We know that measurement will be
15 used to help people make informed choices, so
16 that we want to be able to give them some
17 guidance about how to select wisely, that will
18 reflect their best interest.

19 We have a whole host of purposes for
20 measurement. So I think we need to think
21 about what we can measure, and we're focusing
22 today on patient-centered family-centered

1 care, and that's what we need to look at. I
2 think that it's useful to think whether these
3 -- how these measures fit into the large and
4 cold.

5 That's part of what this schematic
6 looks at. It's one part of a larger
7 measurement structure. Indeed, most health
8 care is managed by individual outside of the
9 health care setting.

10 But when we think about the purpose
11 of measurement, we're not looking at that
12 right away, except to the extent that the
13 system supports that. That's a legitimate
14 area of concern, I think.

15 But I think we need to be -- I think
16 we need to have some perspective about the
17 breadth of the scope, and what we can
18 realistically expect to accomplish here, and
19 what we ought to be focusing on. I think
20 Kevin gave us our marching orders. I think he
21 was very clear about that.

22 CO-CHAIR OKUN: So I just want to

1 remind us we're eating into our break, so just
2 for the comments. So Maureen and then Ethan,
3 and then we'll break.

4 MEMBER CONNOR: Okay. It's between
5 me and the break, so I'll be quick. I just
6 wanted to comment, relative to all of the
7 discussion around the settings of care, where
8 health care is delivered, and to touch on
9 something you just pointed out, which is the
10 vast majority of health care is delivered in
11 the patient's home, in the kitchen, in the
12 bathroom, with the ten bottles of medications
13 that families are left dealing with. So I
14 think that's something we need to remember.

15 MEMBER BASCH: I totally agree with
16 that, and out of sight is often out of mind,
17 unfortunately. I was just going to comment.
18 You know, much of this is related to culture
19 and entrenched processes that are related to
20 the way that we have done things for many,
21 many years.

22 We're really talking about

1 informatic solutions to entrenched cultural
2 problems or processes. As I think about my
3 colleagues, right, who are physicians, nurses,
4 administrators, we're not trained to be
5 patient-centered. We're not trained to
6 emphasize the patient experience or
7 perspective.

8 We have inadequate resources to do
9 so, even when we're very caring, empathetic
10 people, and it's not a priority where we work.
11 As a result, you know examples like the one
12 that Kevin gave, that's really a triumph of
13 the sheer will of an individual to overcome
14 insurmountable odds related to these, you
15 know, entrenched processes.

16 And so you know when I think about
17 measurements, one of my impressions from the
18 comments going around the room this morning is
19 a lot of people say oh goodness, measurement.
20 This is such a burden to us. You know, here
21 we are. We really want to do the right thing,
22 but now we have yet even more than we have to

1 do.

2 I think, you know, I think the
3 subtext there is, you know, I really hope this
4 isn't going to be another one of those things
5 that we all have to do, where you know, the
6 outcome isn't the desired outcome, and we just
7 wind up being yet even more burdened.

8 So you know, to me taking a step
9 back, you know, my hope is that we can
10 actually empower those individuals in health
11 care settings, who really want to convince
12 other stakeholders in their organizations that
13 it's in everybody's best interest to include
14 the patient perspective and to include
15 patients.

16 So you know, for either a provider
17 or an administrator who wants to say "Look,
18 you know, we have to get patients into the
19 room sooner. We have to train our medical
20 students and residents not just to talk at our
21 patients, but to listen to them. We have to
22 use measures that help us to understand

1 patient's decision-making preferences,"
2 etcetera, etcetera, whatever it's going to be
3 from the bottom up.

4 But you know, I think that it's
5 dicey, because one can wind up just creating
6 measures that create burden rather than
7 empower. So it's comments. I'm not sure I
8 know exactly how to do it, but I do hope that
9 we'll think about that.

10 MS. PACE: Okay. Well let's take a
11 ten minute break, and be back here at 10:35,
12 so we can get on with our agenda, and thanks
13 for all your comments so far.

14 (Whereupon, the above-entitled
15 matter went off the record at 10:25 a.m. and
16 resumed at 10:35 a.m.)

17 Definition and Core Concepts

18 MS. PACE: We're going to reconvene.
19 We're going to get started. Thank you, Uma.
20 I think before we start our next session,
21 Maureen wanted to make a comment to Ethan's
22 last comment.

1 MEMBER CONNOR: Thank you. I noted
2 when Ethan was talking before the break, he
3 mentioned the burden of measurements on health
4 care organizations, and that's very real. You
5 know, health care organizations are drowning
6 in the number of things they have to measure
7 these days.

8 But just to put a different slant on
9 this, at the seminar I was teaching at last
10 week in San Francisco, there is a crying need
11 on the part of health care organizations to
12 have measures, because they truly want to
13 measure this, and they truly want to be able
14 to share this with others, to really sell the
15 notion of person- and family-centered care,
16 because a lot of organizations don't quote-
17 unquote "buy into this," and they want to see
18 what the bottom line is, etcetera. So I just
19 thought I would share that aspect.

20 CO-CHAIR KOTAGAL: Thank you,
21 Maureen. That's a good caution. I think --
22 yeah.

1 MS. PACE: We're going to start our
2 next session on the Definition of Core
3 Concepts, and Uma's going to facilitate it.

4 CO-CHAIR KOTAGAL: So I just wanted
5 to say that at break, I was thinking about our
6 conversation, and felt a little sober about
7 all of the ways in which things could go
8 wrong, and really thought oh my God, what have
9 I gotten myself into.

10 But I think I am certainly reassured
11 by Dave and others that our task here is not
12 to define the measure. Our task here is to
13 say what should be measured. So for all of us
14 measurement experts, it not our job to get
15 really complicated about this, as we look
16 through the concepts of person-centered care.

17 Our task is simply to say of all of
18 this, I think this is the important thing, and
19 then thank God, Karen and everybody else at
20 NQF, will go away and wave a little magic wand
21 and come back with the answer to the questions
22 that we raise.

1 So for everybody that's kind of now
2 thinking oh my God, what's the burden going to
3 be, our job is only to say what is important
4 to be measured, and in that context, I want to
5 be sure that the patients and the
6 representatives of patients in the room,
7 please speak up.

8 Please react to what the providers
9 and professionals and researchers are saying,
10 so you can keep us grounded in what's really
11 important.

12 So again, our job is only to say
13 what should be measured, not how we do it and
14 what the measure is. That's really the work
15 of NQF that will come back and do that. So
16 with that in mind, I want to take a few
17 minutes to look at the draft definition in
18 front of you for person- and family-centered
19 care, and just review the draft and review the
20 core concepts, and then take a few minutes for
21 discussions, which I know will be robust.

22 So an approach to planning and

1 delivery of care across settings and time,
2 that is centered around collaborative
3 partnerships amongst individuals, their
4 defined family and providers of care. It
5 supports health and well-being by being
6 consistent with, respectful and responsive to
7 an individual's priorities, goals, needs and
8 values.

9 So it's a fairly comprehensive, all-
10 encompassing definition of this partnership
11 and this relationship. If we can go to the
12 next slide, there it is, that these are some
13 of the core concepts. What I think we'll do
14 after we have our discussions, have different
15 people in the group really talk about, from a
16 personal or from a story point of view, how
17 they see a particular concept.

18 So the first one is that my care
19 partners strive to know me as a whole person,
20 to take into account my priorities and goals
21 for physical, mental, spiritual and social
22 health, and I think this morning we covered

1 some of that during our discussions.

2 The second is I received the care I
3 need no more, no less where, when and how I
4 prefer, and many of you made reference to the
5 fact that the home may be the greatest place
6 where really a lot of this happens.

7 My care partners treat me and my
8 family with respect, dignity and comparison.
9 I think you made reference to the lack of
10 compassion, the lack of sort of being seen as
11 a whole person, as part of the conversation.

12 I collaborate -- and this one we
13 spent a lot of time on. I collaborate in
14 decisions about my care, to the extent I
15 desire or am able, or I choose a care partner
16 I prefer to collaborate in those decisions for
17 me. So explicitly saying "I get to decide how
18 this is going to happen, and I get to decide
19 who's going to help me make it happen the way
20 I want."

21 My family care partners include
22 those I choose, and their role is supported by

1 other care partners. So again, I'm in the
2 driver's seat. I'm going to decide how this
3 happens. So let's take a few minutes and
4 think through that.

5 (Off mic comment.)

6 CO-CHAIR KOTAGAL: My care partners
7 provide information in the format I prefer, to
8 answer my questions and help me understand my
9 choices about my health, health problem,
10 treatment, care, cost or providers, and they
11 increase my confidence and capacity to care
12 for myself to the extent that I am able.

13 My care partners value my time and
14 use it efficiently and effectively, back to
15 the comment about moving from the waiting room
16 to the exam room, and then spending, you know,
17 some time there.

18 Then communication with and among my
19 care partners is honest, transparent and
20 coordinated across settings and time. So
21 these are the core concepts I think that we
22 are talking about when we're thinking about

1 person-centered care, and with that, let's
2 open that for some comments or questions.

3 FEMALE PARTICIPANT: Karen, you may
4 have something.

5 MS. PACE: Yeah. We're going to --
6 what we're going to do now is have the
7 vignettes. We have one person that's going to
8 spend about five minutes to give a little
9 vignette that exemplifies the core concept,
10 and then we'll have discussion period, and
11 then that will be followed by a panel, where
12 we'll have the patient and patient
13 representatives specifically addressing what
14 their reaction to the definition and core
15 concepts.

16 So let's go to the first one, and
17 Gene Nelson was going to share some things
18 with us for this one.

19 MEMBER NELSON: Well thanks for this
20 invitation. Karen and Mitra asked me to focus
21 on that first concept. "My care partners
22 strive to know me as a whole person, and take

1 into account my priorities and goals for
2 physical, mental, spiritual and social
3 health." That's a pretty tall order.

4 I thought about where to locate a
5 case. I contacted my friend, Dr. Joel Lazar,
6 who's the chief medical director of Dartmouth
7 Health Connect, and he provided a case that
8 I'll read to you, and then I'll just give you
9 a background about what makes the case
10 possible.

11 Molly's a 50 year-old woman with
12 chronic disabling pain of her back and knees.
13 She's the primary caregiver for her ailing
14 mother, and she has lost two of her five
15 siblings to tragic circumstances. As a
16 newcomer to the Upper Valley, that's our area
17 of Dartmouth, Molly experienced isolation and
18 struggled with depression and alcohol misuse.

19 Molly was fortunate to establish a
20 primary care relationship at Dartmouth Health
21 Connect, a practice whose explicit mission is
22 bringing humanity back to health care. She

1 presented for the first time in a state of
2 extreme mental anguish due to physical and
3 emotional pain. She found an immediately
4 comforting environment, and a tightly
5 integrated care team.

6 At this very first visit, she met
7 with her new physician, her nurse, a personal
8 health coach and an onsite behavioral health
9 specialist. Members of this care team have
10 continued to partner actively with Molly to
11 weather specific challenges, and to address
12 personal goals that she herself prioritized.

13 During this period of emotional
14 stress, Molly lost her driver's license, due
15 to an episode of DWI. Her primary care team
16 did not lose faith in her, but doubled down
17 efforts to support and empower her. Because
18 Molly was unable to drive to her orthopedic
19 specialist's appointment, her health coach
20 took a morning to drive her to and from that
21 visit an hour away.

22 This specialist encounter proved

1 essential for subsequent scheduling of
2 necessary pain-reducing surgery. On the drive
3 home from that appointment with Molly's
4 permission, the coach drove an alternate
5 scenic route, stopping at a mountain view,
6 which gave Molly space and quiet time to
7 recenter herself. Molly still recounts that
8 day as meaningful and transformative.

9 In addition, when Molly experienced
10 a brief period of homelessness, it was her
11 care team that helped Molly to seek her not
12 only new housing for herself, but also a good
13 shelter for her dog, which was for Molly a top
14 priority.

15 Finally, recognizing that steady
16 employment would be essential to Molly's well-
17 being, her health coach met with Molly one on
18 one on several occasions, to train her in job
19 interviewing. Her coach also helped her to
20 edit her resume for her ultimately successful
21 job search.

22 Molly continues to work on mental

1 health issues, but now does so with regular
2 support from her care team. She is highly
3 engaged. She voices a growing sense of
4 empowerment, which links her feelings of
5 partnership with her clinical team.

6 She's graduated from the homeless
7 shelter to her own apartment, has returned to
8 work with improved mood. While her road ahead
9 is bumpy, she experiences her days with
10 greater confidence and hope, and with
11 substantially less physical pain, emotional
12 burden and social isolation.

13 So that's a vignette. It was
14 selected by Joel to try to represent a whole
15 person care. What's underneath the story is
16 an innovative primary care practice, that has
17 some important characteristics. So first,
18 it's primary care capitated. So that care
19 across different settings and in different
20 ways is open and expected.

21 Second, as you saw there's a care
22 team. There's a physician, there's a health

1 coach, high school graduate generally with
2 special training, and a personality that is
3 right for the job. There's an embedded
4 behavioral health specialist, and then they
5 run these processes, these routine things.

6 So there's a daily extended huddle,
7 40 minutes every morning, all staff, talking
8 about what's up for the day, the patients that
9 they'll be seeing, as well as patients that
10 they're worried about. Besides the extended
11 huddles are every day, they have -- every two
12 weeks they have mental health and population
13 health work rounds.

14 So there's skills training in mental
15 health techniques, as well as shared decision-
16 making and methods to help patients become
17 more empowered. Similar population health
18 rounds on how do you actually coordinate care
19 for tough, multi-cormorbidity patients in our
20 neck of the world.

21 Finally, and fourth, there is
22 systematic and repeated use of patient-

1 reported outcomes. At the end of every visit,
2 a person is sent an email, and asked three
3 questions. Would you recommend us, scale 1 to
4 10; how did we do in providing your care
5 today; any ideas for making care better.

6 And then there's the periodic and
7 repeated use of health assessment, I think
8 PROMIS, getting physical health, mental
9 health, health-related quality of life and
10 health risk, as well as my personal goals.
11 What am I most concerned about with my health;
12 what am I most -- what do I most want to work
13 on?

14 Lastly, there is a patient advisory
15 group that meets with the practice at dinner
16 quarterly. So that's the vignette, Karen.

17 MS. PACE: Thank you. So I think
18 what we'll do is go through each of the
19 vignettes, and then we have time for all of
20 the committee to discuss and ask additional
21 questions and clarifications. So Uma, I think
22 you're next.

1 CO-CHAIR KOTAGAL: So the one that
2 Karen asked me to talk about is the care I
3 need, no more, no less, when, where and how I
4 prefer to get it.

5 The story I have is about Darryl.
6 Darryl's a nine year-old with severe
7 persistent asthma. Darryl's first admission
8 was when he was seven. He has about four to
9 eight ED visits a year but no ICU admits. His
10 dad and younger sister have asthma. His
11 medications are several, and Darryl takes them
12 sometimes, and his triggers are activity,
13 changes in weather, tobacco and dust.

14 He was just getting admitted the day
15 that we talked to him. He lives with his mom
16 and siblings. He's relocated again, due to an
17 apartment fire, and mom's boyfriend did not
18 move with Darryl and his mom due to domestic
19 violence. Darryl spends weekends with his dad
20 and his girlfriend, but his aunt and grandma
21 also care for him.

22 Sometimes Darryl has difficulty

1 getting his medications refilled due to
2 insurance denial. His new apartment is pretty
3 old and dusty, and might have mildew in the
4 basement. Darryl's sister has bipolar
5 disorder, and Darryl's mom has to spend a lot
6 of time taking care of her.

7 Darryl is nine and can sometimes
8 forget to take his medications. Every third
9 weekend or so he has to sit, go and live with
10 his grandmother, and sometimes he forgets to
11 take the medication when he goes there.

12 So how do we think about designing a
13 system for Darryl, and what does that look
14 like? So the primary care clinic really began
15 to understand Darryl a lot better, by asking
16 the right questions about the details of some
17 of this information, that helped them
18 recognizing that simply discharging Darryl
19 from the hospital with a prescription was not
20 going to work.

21 So the first thing they did was to
22 repackage his medications that he used in the

1 inpatient setting for use in the outpatient
2 setting. So when he went home, he had his
3 medications, because the commonest thing
4 happening was Darryl was coming back three
5 weeks later, because he hadn't filled his
6 medications.

7 The second thing they did was not to
8 have the respiratory therapist do the usual
9 talk to you in the inpatient unit, four hours.
10 You know, once the inhaler duration is
11 extended and just repeat one more time, what
12 Darryl need to do.

13 Instead, they had a home visit.
14 They spent more time at the home. They looked
15 at the home. They sorted out what needed to
16 happen and through this pathway they were able
17 to teach Darryl and his mother much more
18 systematically and clearly what was needed.

19 I think the third thing they did was
20 to find a local pharmacy in the inner city
21 that would deliver the refills to Darryl,
22 because once they were discharged home,

1 Darryl's problem was not getting his refills
2 filled, and this pharmacy does deliver and is
3 linked to the Medicaid database, and allows
4 his team to know that Darryl did get the
5 medications.

6 But also looking at the home and
7 understanding that the home, and understanding
8 that there was mold in the home, there were,
9 you know, other issues that caused Darryl a
10 problem, working with Legal Aid to really
11 figure out how to find Darryl and his mom an
12 apartment working at -- taking the landlord,
13 that sort of had actually many buildings in
14 the area that all had kids, and we began to
15 notice that a number of the kids were getting
16 admitted.

17 When we sorted the zip code, we
18 found that there were actually landlords in
19 several buildings that were not sort of taking
20 care of their buildings. Then, you know,
21 working with the school nurse, so that when
22 Darryl is in school, the school nurse knows

1 and can intervene, can recognize and can
2 reinforce it.

3 Finally, a lay coordinator that
4 really works with Darryl and his mother, so
5 when Darryl's mother is concerned, that
6 there's a call to somebody that can help
7 manage and think about what Darryl needs.

8 So I think Darryl now plays
9 basketball. He wants to be a policeman, and
10 he's doing really, really well. So thinking
11 about how to solve Darryl's problem, not in
12 the traditional sort of model. I think Gene,
13 many of the comments you made about a primary
14 care system that's population-based, that
15 understands each kid, that has same day, you
16 know, ill day access, home visits and
17 coordination.

18 Then for kids, the working between
19 different settings, not really just thinking
20 about the health care system. Back to Chris'
21 comment, really thinking about the broader
22 system for kids, where they live and what does

1 it take for Darryl to be healthy and be able
2 to play basketball and grow up to be a
3 policeman.

4 MS. PACE: Thank you. Okay, next we
5 have Annie.

6 MEMBER WALLING: Okay. So the core
7 concept that I'm going to talk about is my
8 care partners treat me and my family with
9 respect, dignity and compassion. So this is
10 -- oh sorry.

11 So okay. So this is a very broad
12 concept. So I tried to think of a common
13 every day example, of how care -- I actually
14 used an example in the inpatient setting,
15 about how care may not always represent this
16 core concept, and then I was going to list
17 some of the best practices that may change
18 this problem scenario into more improved
19 scenarios.

20 So Mr. L was diagnosed with advanced
21 non-small cell lung cancer about six months
22 ago, and is currently on an inpatient medical

1 ward for pneumonia. He has been followed by
2 his outpatient oncology clinic, and has been
3 receiving chemotherapy. This chemotherapy has
4 been held while he's in the hospital.

5 He has not had any conversations yet
6 with his medical team about his prognosis or
7 his overall goals of care. He's become more
8 anxious about his cancer diagnosis, because of
9 increasing pain and shortness of breath, and
10 is really worried about what will happen next.
11 He is afraid of dying, and is having a hard
12 time talking with his family about his cancer.

13 So far, he and his oncologist have
14 been focusing on fighting his cancer, but this
15 hospitalization in particular is really
16 worrying him. He has spent much of his
17 savings account on co-pays and treatment, and
18 is worried about his finances.

19 Inj the hospital, he's been given
20 fluids and antibiotics, and some doses of
21 morphine. His fever, pain and shortness of
22 breath have improved during his three-day

1 hospital stay. So at 6:00 a.m. on his third
2 day in the hospital, Dr. M enters into the
3 room without knocking and wakes him up to ask
4 him about his symptoms.

5 The doctor asks "Are you doing
6 better this morning, Mr. L?" He replies yes,
7 but I am pretty anxious about all this. The
8 doctor does not address his anxiety, and
9 replies "So your pain and shortness of breath
10 are both better?" After the patient says yes,
11 he quickly examines Mr. L without closing the
12 curtain for privacy, and says you can go home
13 today and follow up with your oncologist.

14 So this list is not an exhaustive
15 list of some of the best practices that may
16 represent this core concept, and it may have
17 some overlap with some of the other core
18 concepts. But providing information and
19 support in a timely fashion, tailored to a
20 patient's needs of readiness; providing common
21 courtesies such as knocking and privacy;
22 responding to emotion with empathy; and

1 providing high quality communication and
2 psychosocial support; being aware of the
3 patient's needs including social, spiritual
4 and economic needs; and identifying needs that
5 can be made by medical or community resources
6 for the patient and/or the family.

7 So okay. So an improved scenario
8 may be Mr. L has advanced non-small cell lung
9 cancer, and he's currently on inpatient ward
10 for pneumonia. He's been followed by an
11 outpatient oncology clinic and has been
12 receiving chemotherapy.

13 He understands his disease and
14 prognosis, and feels supported by his
15 oncologist and outpatient palliative care
16 team. He's focused on finding his disease,
17 and he has a teenage son and is looking
18 forward to this high school graduation this
19 spring.

20 He's been working with a social
21 worker, who is part of his outpatient team,
22 who has been helpful in providing resources

1 that have limited financial strain and a
2 chaplain has also worked with him with some of
3 his spiritual concerns and helped to refer his
4 son to a support group, which has helped the
5 family a great deal.

6 At first, it was difficult, but over
7 time, he's been able to have open
8 conversations with his family, with the
9 support of his interdisciplinary medical team.
10 Still, this recent hospitalization has made
11 him quite anxious, and he wants to talk to his
12 oncologist, because he has a lot of questions
13 about specific details and what's going to
14 happen next.

15 So in the morning, this time it's
16 8:00 a.m. instead of 6:00 a.m. on his third
17 day. Dr. M knocks and the patient indicates
18 that it's okay for him to enter. The doctor
19 asks Mr. L how he's feeling. He says I'm
20 feeling better, but I'm pretty anxious about
21 all this.

22 So this time the doctor says "I know

1 it can be hard being in the hospital. What
2 can I do to help you?" They talk briefly
3 about his concerns, and decide to set up a
4 meeting later on that day with the palliative
5 care team and the oncologist.

6 So Mr. L feels listened to, less
7 anxious, knowing that he has a plan or that
8 he'll be able to come up with a plan with his
9 care team before leaving the hospital.

10 MS. PACE: All right, thank you.
11 Okay, the next one? All right, Michael.

12 MEMBER LEPORE: So the concept I was
13 asked to present on is the patient and I
14 collaborate in decisions about my care, to the
15 extent I desire or am able, or I choose the
16 care partner I prefer to collaborate in those
17 decisions for me."

18 I reached out to several Planetree
19 hospital members for examples about this, and
20 what I found was that there was a lot of
21 overlap across many of the concepts, and I
22 really wanted to keep it narrow on this

1 concept, and the overlap. So I said okay,
2 well it's actually a full culture of change
3 has happened in these places.

4 So I reached out to a different
5 group of colleagues, Dementia Action Alliance,
6 which I've shared a previous -- the
7 development of a definition of a person-
8 centered dementia care. I'm going to share
9 one of these examples.

10 Actually right now, there is
11 Alzheimer's Association policy forum event
12 occurring in D.C., and a woman named Myriam
13 Marquez is visiting. She lives in Seattle,
14 and she's helping lead the development of a
15 dementia friendly community in Seattle. She's
16 working with the Parks and Recreation
17 Department and other advocates.

18 She is a beautiful 68 year-old,
19 vibrant woman, as I've been told, and the
20 paternal side of her family has the early
21 onset gene for Alzheimer's. Half of her
22 siblings have already manifested symptoms,

1 including her 49 year-old brother. Her father
2 died of Alzheimer's, as well as eight of her
3 12 aunts and uncles.

4 Myriam has a spirited proactive
5 attitude about her condition, because she is
6 in charge of all of her decisions. Her grown
7 daughters are in full support, and this gives
8 her joy, because she knows that when the time
9 comes that she can no longer actively make
10 decisions, her daughters will do so, in a
11 manner that fully respects her personhood and
12 her interests.

13 The key aspect to this story is not
14 just about planning and for decision-making,
15 but that there's this driving and ensuring
16 that the decisions are made that will be based
17 on Myriam as a human being with specific
18 interests and specific preferences, that are
19 aligned with her emotional and mental well-
20 being now, as well as later when she's unable
21 to make decisions herself.

22 So there's this really, I think,

1 time frame built in of the short-term ability
2 to make decisions now, the long-term planning
3 for those decisions to be made in the future,
4 and I thought this was a really different
5 story than many of those that I heard, that
6 were really focused on provider-patient
7 interactions at one point in time.

8 MS. PACE: Thank you, and next we
9 have Jennifer Wolff, who's going to talk about
10 family.

11 MEMBER WOLFF: So the concept that I
12 was asked to talk about is "My family care
13 partners include those I choose, and the role
14 is supported by other care partners." So this
15 concept in my mind reflects the notion that
16 some patients navigate health care processes
17 in a broader family context, and that in the
18 ideal state of a patient who has capacity and
19 the support of family, their patient wishes
20 should drive decisions about family
21 involvement, and the care providers would
22 ideally respect and support patient wishes,

1 both to include as well as exclude family
2 members.

3 By extension, this concept, I think,
4 raises the notion that patients and family
5 members are distinct individuals, and they
6 have different needs, priorities, preferences
7 and values. I think challenges to the concept
8 come from the fact that patients and family
9 members' needs, priorities, preferences and
10 values may diverge.

11 Some patients do not have capacity,
12 and that some patients rely on a family member
13 to navigate the health system. So I guess to
14 what extent is the health system responsible
15 for supporting both the patient and the family
16 member who's supporting the patient's care?

17 In terms of a vignette, I turned to
18 a resource which is a wonderful book by Susan
19 McDaniel called Family Oriented Primary Care,
20 and there are -- this book has many, many
21 examples and resources across the life course.
22 The examples in the book largely all reflect

1 this common theme of proactive health system
2 involvement, to support the patient and the
3 family member.

4 So proactively supporting both to
5 resolve issues, both when a family member is
6 a barrier to care, or when the patient
7 preferences may imply overly burdensome
8 responsibilities for the family.

9 So I had lots of different
10 vignettes. Karen, many of them reflected poor
11 quality care. Karen said I should be looking
12 for exemplars. So I'm going to read one
13 exemplar where the family -- where the
14 physician basically harnesses the family, who
15 was not super-supportive in helping the
16 patient, and strengthens the partnership.

17 So a new patient, Mr. Samuel, is a
18 30 year-old Romanian bricklayer, who was
19 prescribed medication and a low salt diet for
20 his hypertension by Dr. L. Mr. Samuel's
21 parents, with whom he had emigrated and now
22 lived, had doubts about the efficacy of

1 medical treatment. They questioned the
2 medication, and felt the diet would mean their
3 lifestyle would have to change too.

4 Mr. Samuel, the patient, was caught
5 between opposing expectations from his
6 physician and his parents. He resolved the
7 dilemma by complying with the treatment plan
8 only in part. He took his medication
9 irregularly and followed his diet for a few
10 days.

11 Partial compliance ironically
12 convinced both the doctor and the family that
13 each was right. The doctor saw it as a
14 confirmation the patient must try harder. The
15 family was convinced the treatment was not
16 working. Both sides escalated their
17 positions, and the patient continued his
18 compromise.

19 In the meantime, his blood pressure
20 remained elevated. The doctor soon recognized
21 the situation and invited the patient's
22 parents to come in with him. He explained

1 their son's hypertension and the rationale for
2 the treatment plan. He enlisted their help,
3 clearly indicating they could bring about some
4 change for their son.

5 The patient's mother was utilized as
6 an expert on diet. The parents gave their
7 permission for the son to take the medication.
8 So in this example, by being proactive, the
9 physician works through a less optimally
10 supportive network.

11 I had other examples that I will not
12 go into for time's sake, but that touched on
13 the issues around dementia and dementia
14 caregiving, both egregious examples of where
15 dementia caregivers is so overly burdened that
16 they have no quality of life, and an exemplar
17 from the McDaniel book, where the physician
18 interacts with the family members and
19 understands that they're struggling, and
20 brings the patient and the family members to
21 come to a compromise. I think that's it.
22 Thanks.

1 MS. PACE: Okay, thank you, and next
2 we have Bruce Leff.

3 MEMBER LEFF: So I have the longest,
4 in terms of number of words item, and it
5 focuses on the format that folks want their
6 information in. So I have three micro-
7 vignettes. The first is about myself. So I'm
8 seen at a world class ophthalmologic hospital
9 in Baltimore that shall remain nameless.

10 I have a very quick laser procedure,
11 where the ophthalmologist basically plays a
12 video game on my posterior capsule. Have an
13 amazing, wonderful result, instantaneous, and
14 before he did this, he said you know, you're
15 going to need to take a drop in your eyes
16 afterwards.

17 I said could you please write this
18 down for me, because I am anomic. I won't
19 remember any of your names. I am anomic. I
20 cannot remember names, I can't remember names
21 of medicines that people tell me about
22 quickly. I said please write that down. He

1 said don't worry; we have this wonderful thing
2 called EPIC. It will be in your after-visit
3 summary.

4 Great. I go to the front desk. The
5 computer's down. I figure all right. I'll go
6 to the pharmacy. I go to the pharmacy. There
7 are two drops in the bag. You know, what do
8 you do? You can't get through. I happened to
9 have his phone number and I texted him, and he
10 said you're right, only one, and he told me
11 which one to take.

12 Second vignette. A middle-aged
13 physician patient of mine, a world-renowned
14 expert, infectious disease expert I see about
15 nine or ten days ago, I diagnose acute
16 diverticulitis, so a colon inflammation. She
17 is someone who only wants to be contacted
18 outside of the office via email.

19 She emailed me last night. I was
20 getting better, now I'm not better, you know.
21 What now? Email back and forth. This is
22 really not ideal for me as the provider, and

1 we're sorting it out, and I'm sorting it out
2 still. But she appears to be getting better,
3 which is good.

4 The vignette, two patients of mine
5 who I used to make house calls to, both with
6 multiple chronic conditions. One with both
7 legs amputated below the knees for vascular
8 disease; the wife with cognitive impairment,
9 living in a classic Baltimore row home,
10 require medication adjustments constantly.

11 They don't really want a whole lot
12 of information. Family is, you know, in the
13 wind and kind of getting involved from time to
14 time. It turns out that the person who can
15 really help with this is the neighbor, who
16 comes and looks at them each day.

17 How do I communicate with her? She
18 doesn't want to be contacted with my by phone.
19 Only wants to see me when I make a visit to
20 the home, and then only wants to get new
21 information on how to give the medicines by me
22 writing on the bottle itself, which by the way

1 you can only reconcile medications with the
2 bottle in hand. Editorial comment.

3 Family kind of calls in at times,
4 thinking they're part of the equation. But
5 they never really identify someone that would
6 actually make it easy for me to be efficient.
7 So a few lessons here. I think patient values
8 and preferences really are important, but
9 don't always optimize care, right.

10 So things could be better if we were
11 doing things as partnerships. Health system
12 issues matter. One size does not fit all when
13 it comes to this. I think there needs to be
14 some bidirectionality between patients and
15 providers on how to optimize this.

16 Some issues are not easy to address.
17 So for instance, in that long text, the word
18 "costs" appears. It is really hard for anyone
19 to know what anything costs in health care,
20 right. I can say I think that thing is going
21 to be really expensive, but I would say even
22 within health systems, you don't know if the

1 colonoscopy done, in which building within a
2 health system might have a factor of five or
3 ten in terms of difference in cost.

4 I think it's also very challenging
5 to include all the patient's partners, even
6 identifying the partners for care at times.
7 So I'll stop there.

8 MS. PACE: Thank you, and next we
9 have Dave deBronkart.

10 MEMBER deBRONKART: No single
11 vignette again could possibly handle this. I
12 have -- they'll all be quick obviously. I
13 have three negatives and four that show that
14 it can be done, and one bottom line lesson
15 from a great leader.

16 At my primary care practice, where I
17 get my care, I love my doctor. The practice
18 stinks. It does. It's Health Care Associates
19 at Beth Israel Deaconess. I've spoken about
20 this to them and to my doctor. This is all --
21 none of this is gossip or mudslinging. It's
22 an ongoing conversation.

1 I chose to stay there because my
2 relationship with that doctor is so important,
3 and you know, I said earlier we ought to ask
4 how is it working out for you as a patient.
5 I say we also ought to ask how is working out
6 for you as a doctor, right, because the junk
7 is the stuff in between, all right, and that's
8 like the second elephant in the room.

9 Well anyway, so earlier I mentioned
10 my mother's experience. Clearly no respect
11 for her time, you know. They put her in the
12 room and let her wait 45 minutes.

13 Morgan Gleason is a 15 year-old who
14 a couple of months ago had an episode where
15 she was so frustrated as an inpatient that her
16 mom took out her iPhone and recorded this two
17 minute video, which went viral -- I put it on
18 Forbes, and has over 100,000 views, where she
19 just said it's just -- she's trying to get
20 sleep, which in a sense I say, I assert that
21 the core question of do you value my time is
22 do you attach importance to how we spend our

1 time together, and how I spend my time.

2 Like I'm sick, I'm in the hospital,
3 I need to sleep, right. Planetree has been
4 exemplary about this for decades. Most
5 hospitals ignore the issue, all right, and so
6 those are the three bad things. And that two
7 minute video, by the way, if you haven't seen
8 it, it just nails patient-centered thinking.

9 Exemplars, okay. The Orthopedics
10 Department at my hospital, Beth Israel
11 Deaconess, reduced waiting time something like
12 80 percent by going through a lean process
13 that involved only changing the paper work,
14 how papers are put in baskets on the doors of
15 the rooms.

16 It can be done, all right. Primary
17 Care Progress is a new -- well, it's a couple
18 of years old initiative, where patients who go
19 into one of their practices are seen and
20 they're doing something meaningful with the
21 clinician within two minutes of walking in the
22 door. It can be done. Open Notes, the Robert

1 Wood Johnson for -- that study does the world
2 fall apart and go to hell in a hand basket if
3 patients get to look at their doctor's visit
4 notes, all right, respects my time in the
5 sense that I was one of the guinea pigs.

6 A couple of weeks after a visit, all
7 right. See, they give me a discharge summary.
8 Thank you so much. Ask me a week later where
9 it is. I'm sorry. Well, so I had -- and
10 sure, you can blame me. Anyway, I thought I
11 was supposed to follow up on something.

12 What was it, and I could have tried
13 to remember the next morning on my way to work
14 or something, to call in and have some go
15 look. See, this respects their time too.
16 Have somebody go look, what was it he was
17 supposed to follow up on?

18 Instead, I went online within one
19 minute and found oh yeah, that crusty thing on
20 my scalp. So I was more compliant with less
21 utilization of resource by the practice. It
22 can be done, and then finally a couple of

1 years ago, I was doing a series of speeches in
2 Spain, and at one dinner meeting, somebody
3 said "Oh come. You have to meet Dr. Cassado."
4 Dr. Cassado tweets to his patients when he's
5 running behind schedule, right.

6 I call ahead and ask Health Care
7 Associates how's Dr. Sands doing? They can't
8 tell me, right, and they don't see why I would
9 want to know. Just come in, all right. So it
10 can be done, and this leads me to my
11 punchline.

12 See, the attitude, people ask me
13 this ePatient thing. What does empowered
14 really mean? Well, the hallmark of a
15 disempowered person is somebody who says well,
16 there's nothing we can do, all right, and the
17 people in that practice who say there's
18 nothing we can do about this are disempowered,
19 and it brings me back to the big lesson Jim
20 Conway said at the HRO conference a couple of
21 weeks ago in his keynote.

22 "Nothing drives change more than the

1 leaders who say we will," all right. I wonder
2 given that it can be done and so many people
3 don't, I don't think we ought to be poking the
4 finger -- pointing the finger at the people in
5 the practices. I think there's some CEOs who
6 need their butts kicked, you know.

7 They ought to have a quality measure
8 delivered to them that why are you not -- the
9 same thing, of course, applies to all the
10 patient safety issues, the harm. So that's my
11 series of vignettes.

12 MS. PACE: Thank you. Very helpful,
13 and last but not least, Troy.

14 MEMBER FIESINGER: Okay. So the
15 lesson is turning 40 is bad for you. So
16 basically this is --

17 FEMALE PARTICIPANT: It's too late.

18 MEMBER FIESINGER: I know. So this
19 is my experience from my family's horrible,
20 terrible year, where we started the year with
21 my mother having emergency bowel surgery for
22 bowel obstruction at New Year's, having post

1 op delirium. She's hard of hearing, she has
2 an anxiety disorder. You can imagine the
3 things she put together in her brain from what
4 the caregivers did and did not say.

5 Then I had a bicycle accident. Then
6 my father fell off a ladder and broke his
7 back. My brother so far has been unscathed,
8 but he's looking both ways when he crosses the
9 street. So basically I was riding my bike,
10 which I love to do. I tried to avoid another
11 cyclist. I hit a city bus stop going 21 miles
12 an hour.

13 City bus stops in Houston are made
14 of 4 by 4 steel posts with bullet proof glass.
15 You can't break a steel post, and you can
16 almost but not quite break bullet proof glass.
17 So I broke my arm, broke part of my neck,
18 punctured a lung, broke a rib. Found out
19 later that I had torn an artery in my neck,
20 which none of us knew about.

21 So I got first responders were a
22 dentist and a radiologist, who were out

1 walking that day. My wife came, called EMS,
2 and here's the good thing. They said which
3 hospital do you want to go to, because I told
4 him who I worked for and I could chose two
5 ones, the one where I practice, which I know
6 is not very good at trauma, doesn't have
7 enough people on call. I said I'll pick the
8 University hospital. It's a Level 1 trauma
9 center.

10 When I asked for pain medicine, they
11 say well, we can't give it to you. "But you
12 can cuss all you want," because ambulances
13 have really bad suspension, and I know what
14 the roads are between me and that trauma
15 center, because I used to live in that
16 neighborhood.

17 So they got me there, got good
18 treatment, was assessed. My wife said "Hey,
19 what's that big swollen lump on my husband's
20 neck that you guys can't see from the C
21 collar." I said hmm, that's interesting. We
22 should do a scan of that, which is how I found

1 the torn artery.

2 So I'll try to summarize some
3 events. So I was admitted, six days of
4 treatment, had to have surgery. When surgery
5 went twice as long as normal, my wife is
6 basically beside herself with worry. The PA,
7 who was not in the surgery, saw her and said
8 I'll go check what's going on. Came back out
9 and said it was a lot more complicated when
10 the hand surgeon got in there, but your
11 husband's okay. It's just taking a lot of
12 time to put his wrist back together. She's
13 like okay.

14 So that was very helpful to my wife,
15 to just have information, good communication.
16 Then because there aren't any good evidence-
17 based trials on what to do for an occluded
18 vertebral artery, the trauma surgery chief and
19 the neurosurgeons couldn't agree on heparin or
20 no heparin.

21 So heparin goes on, heparin goes
22 off, PT is cutting it on, PT is getting

1 ignored, cutting it on, cutting it off.
2 Papers get brought to me, because this is a
3 pet area of research after they've had a
4 trauma. So there's communication, but I'm in
5 the middle of this little debate.

6 Also, something I learned is when
7 you're sleep deprived, as you alluded, because
8 people walk in your room every four hours and
9 you're on Dilaudid PCA, and your wife is sleep
10 deprived.

11 Whenever someone walks in the room
12 they look at each other and say "Okay, let's
13 try to put together whatever they just told
14 us," because I'm going to forget within five
15 minutes and so is she, and that was a real
16 struggle for us, to just try to remember what
17 we were told.

18 We have, you know, between us like
19 30 years' experience in health care, ten years
20 of graduate education. I thought if we can't
21 figure this out on a good day, Lord help
22 everybody else. So I'm discharged, four

1 months of hand therapy. You know when I say
2 you know, I don't really want to come to the
3 medical center, the traffic is ridiculous,
4 parking costs too much. Okay, we'll find a
5 hand therapist out where you work, so you
6 could go after work. That was good
7 communication.

8 The hand therapist was great, and I
9 spent more time with him than with the hand
10 surgeon. I had to see a neurologist. The
11 neurologist was difficult. First guy I lost
12 as a physician because he got a new grant. So
13 he's going to go off and do research.

14 The second guy I needed elective
15 surgery for an infected cyst and could not get
16 an answer from his office as to whether I
17 could stop aspirin outside of no. Well, if
18 the answer was no, the ENT wasn't going to
19 take the cyst out of my neck. It was kind of
20 this big. I'd like it removed.

21 Phone calls, emails. Phone calls
22 from my providers, nothing, nothing, nothing.

1 Fired him. Got a community neurologist who I
2 refer to a family physician, because I
3 transferred all my care to him, and he said
4 something very powerful. He said "I work in
5 the community. If I'm not nice to my
6 patients, I don't have patients."

7 If he's in the medical center, it
8 doesn't really matter what patients do or
9 don't do, and this is a prestigious university
10 medical center. So I'll just try to
11 summarize. I thought I saw sort of the good,
12 the bad and the ugly at a premier hospital
13 that is in my system.

14 So I'm an employee, and I probably
15 got better treatment. I probably got
16 overtreated also. I'm surprised I don't glow
17 from the number of the CTs that I received.
18 When all the studies came out about excess
19 radiation dosing, I was paying a lot of
20 attention.

21 So the whole aspirin issue was very
22 frustrating. I couldn't get an answer outside

1 of no, and they wouldn't even make me an
2 appointment. Like I'll come in and talk to
3 you. That's fine. So when I said and asked
4 my doctor to send me to a different
5 neurologist, I got in, was seeing the one that
6 I wanted to see.

7 He saw me, he gave me an answer,
8 explained everything to me, and typed a letter
9 that day to the ENT, so I could have my
10 operation. So certainly seeing what is a
11 high-performing system not function very well
12 was challenging.

13 The neurosurgeon versus the trauma
14 on anticoagulation, they were very open with
15 me, which I liked. I mean I'm a doctor. I'd
16 like knowing that there is no evidence on
17 this, and no one really knows what they're
18 doing, and they just have to make a guess.
19 Okay. At least they're honest, that they're
20 just making educated guesses.

21 But having stuff go on and off
22 and people contradicting orders and knowing

1 it's going on, as a physician it's
2 frustrating. As a patient, I'm trying to be
3 calm about this, but this really stinks. You
4 know, just the paramedics saying look, we
5 can't give you drugs, but you can cuss all you
6 want. Okay, at least I know, because this
7 ride -- this five minutes is really going to
8 hurt when you guys hit a pothole, because when
9 you have fractures, anything that bumps you is
10 bumpy to your bones.

11 I'm glad they listened to my wife
12 and said hey, let's scan his neck and find a
13 severe injury. You know, the neurosurgeon did
14 explain to me very transparently, you know,
15 it's a good thing this clotted off, so you
16 didn't have a stroke. Of course, my patient
17 reaction was stroke? Wait, I'm 40. Stroke
18 isn't part of my world view at 40.

19 I feel fine. I mean the most life-
20 threatening thing I've got is the one that I
21 can't even feel. Then life the hand
22 therapist, talking about ancillary providers.

1 The hand therapist was wonderful. He said at
2 the beginning you're going to hate me probably
3 most of the time we work together. I just
4 want to let you know that, with a smile. And
5 he was right; I hated him most of the time.

6 But I also have full use of my left
7 hand from having no use of my left hand, and
8 I thank him tremendously for that, because he
9 was always telling me you're going to hate me,
10 but I'm going to do this because it's going to
11 make you better, and then he had me talking to
12 other patients.

13 Okay, he hates me and you hate me,
14 but his hand's better. See, because I'm
15 sitting at a table next to the guy who had a
16 stroke from an air embolism during his bypass;
17 the woman has had a stroke, and we did our own
18 little sort of group visit while we're all
19 sitting there getting hand therapy, because
20 there's not much to do when your hand's in
21 paraffin. But I was happy to help someone
22 else out, because I really had been through

1 it.

2 Some little vignettes. When my
3 father had the back surgery, this is
4 communication. Yeah, the hospital has talked
5 to us, but somehow he examined my father every
6 day without ever physically touching him,
7 which I find very interesting, and Medicare
8 fraud. But I decided not to pursue that with
9 the hospital.

10 The neurosurgeon was there some
11 days, not others, because I know about
12 payment. He doesn't have to see my father
13 every day. But when his PA came, she
14 explained things well. I think overall,
15 communication's critically important. I know
16 this as a provider. I saw it as a patient,
17 and whenever I think I'm communicating enough,
18 you still find you're not.

19 But it's challenging to do it right,
20 and these weren't -- clinically, these were
21 very good physicians, but communication was
22 all over the map. So I think, you know, your

1 question of asking how was this visit for you
2 is a good one. Being aware of impairment. I
3 mean I basically was impaired the whole time,
4 from just opiates and sleep deprivation.

5 Thank God there was a written
6 discharge order thing handed to me, because
7 when we got home, we had to go to bed , wake
8 up and then look at it to remember what on
9 earth they had said to us. But it would be
10 nice to have it online, to go look it up.

11 MS. PACE: Great, thank you. So we
12 have a few minutes to have some conversation
13 about, you know, anything that that's
14 stimulated. Then we're going to go and hear
15 specifically from our patient and patient
16 consumer representatives. But I just want to
17 see if there were any thoughts that the
18 vignettes provoked, and go ahead.

19 MEMBER deBRONKART: A real quickie.
20 I had the same thing happen when I broke my
21 leg, because of my cancer, and we had an
22 ambulance ride down I-93 into Boston at

1 pothole season. I mean I had morphine that
2 the medics had given me, but still I ended
3 doing a modified Lamaze thing in the back
4 there. The driver would say "here comes
5 another one," and I'd go (breathing heavy) to
6 get through it.

7 But I just dawned on me. Why on
8 earth the ambulances have lousy suspensions?
9 Can't that be fixed.

10 MEMBER LATTS: This is Lisa. Can I
11 just get in the queue?

12 CO-CHAIR KOTAGAL: Lisa, go ahead.
13 Go ahead, Lisa.

14 MEMBER LATTS: Okay. I can't really
15 hear you. Did you say go ahead?

16 CO-CHAIR KOTAGAL: Go ahead, Lisa.
17 Go ahead, Lisa.

18 MEMBER LATTS: Okay. I just wanted
19 to emphasize sort of a theme I heard in
20 several of the vignettes, but I wanted to let
21 you know what's so important from my own
22 personal experience, which is really meeting

1 people where they are, from an empowerment and
2 an engagement perspective.

3 Someone in extremis, someone who's
4 sick, someone who's in the hospital, it's very
5 difficult for them to be empowered and to take
6 charge of their care, depending on what's
7 going on. I think to understand that takes
8 time, and it's something obviously that's not
9 reimbursed, it's not measured, it's not valued
10 traditionally in our system.

11 So to understand what someone's
12 level of engagement and interest in. But then
13 that changes once they're better, once they're
14 well, once they're out in the community. So
15 I think that constant assessment and
16 reassessment of how much do you want to be
17 engaged, how much do you want to be involved,
18 how many decisions do you want to make versus
19 have me make I know to have.

20 I think that that constant
21 reassessment needs to take place and needs to
22 be measured, so that even if we think we know

1 how activated or engaged someone is at an one
2 point in time, that changes, depending on
3 where they are in the health care spectrum,
4 but also what else is going on in other parts
5 of their life, who else is available to help
6 them make decisions, etcetera.

7 So I think as we're thinking about a
8 schema for this, it's not just at any -- it's
9 not just something you do once. It's a
10 constant reassessment. I just wanted to make
11 sure that was noted.

12 CO-CHAIR KOTAGAL: Okay, Bruce.

13 MEMBER LEFF: Yeah. I was pretty
14 impressed that I would say the vast majority
15 of anecdotes were not discrete. There's a lot
16 of leakage across concepts, and I think that
17 that poses some very interesting issues, in
18 terms of, you know, the way we're thinking
19 about our domains and our concepts and our
20 standards, and then getting down to the
21 measurement level.

22 You know, I don't know if it argues

1 at this point for thinking about lumping, but
2 I really think it poses some very important
3 challenges for measurement.

4 CO-CHAIR KOTAGAL: Kevin, I think
5 you're next.

6 MEMBER LARSEN: Yes. Similarly,
7 this is Kevin Larsen. Similarly as I was
8 listening, this was often poised as a system
9 characteristic, rather than an individual
10 person characteristic. So that most of the
11 stories of exemplary work were teams, and they
12 were often teams not even all employed by the
13 same person.

14 I think about the Uma story, that
15 this was a team of people all around a person
16 and family at the school, at the landlord, at
17 the whoever. So I think one of our challenges
18 is also going to be the granularity of
19 measurement, and are we going to be focusing
20 measures on individual health care actors.

21 Is this a doctor, a single doctor
22 measure, a single nurse measure, a single hand

1 therapist measure, or is this a system level
2 measurement that says System A does a really
3 good job of person- and family-centered care,
4 and System B seems to not have all the pieces
5 tied together? Even though it has some
6 fantastic actors like Dave's doctor, the rest
7 of the thing sort of leaves you cold.

8 CO-CHAIR KOTAGAL: That's a great
9 point.

10 MEMBER NELSON: The vignettes were
11 really amazing, and I agree that we saw a lot
12 confluence across the different concepts
13 within many of the cases. We I think the
14 cases repeatedly empathy and caring and the
15 capacity for empowerment, mediated by
16 communication.

17 One of the things that might have
18 been a little bit in the background, but was
19 not probably in the background of Darryl's
20 case and Mr. Samuel's case is this issue of
21 competence or self-confidence in self-
22 management.

1 When you aren't being seen face to
2 face or in the hospital, but you have a
3 condition that's persisting over time, then
4 this issue of confidence and competence in
5 being able to take care of yourself is really
6 critical. Right now, that's sort of a bullet
7 under number six.

8 My sense is it might bear pulling
9 out, because of its importance for certain
10 people in their lives, under certain
11 conditions.

12 CO-CHAIR KOTAGAL: We just go down
13 the line, if you don't mind, and then we'll
14 come back to this side.

15 MEMBER DUBOW: So I thought the
16 vignettes were very interesting and quite
17 poignant. I want to address my comments to
18 what Bruce talked about. Both in terms of
19 your vignette and your last comment about the
20 spillover or the spillage, and I think again
21 we have to remind ourselves -- well, maybe we
22 haven't said it yet.

1 We are not talking about having
2 measures only to assess patient- and family-
3 centered care. The measurement enterprise, if
4 you will, should be looking at other parts of
5 the health care system, and we ought to be
6 evaluating issues around appropriateness, when
7 we can do it; issues around the quality of the
8 care that's provided, the teaminess and all of
9 the rest of that stuff. I mean we are
10 focusing narrowly here.

11 But your point about the fact that
12 really responding to the desires of your
13 patients often leads to what clinicians would
14 consider as suboptimal care, I think, is a
15 real challenge for us. Last night, I re-read
16 Berwick's article on whatever the patient-
17 centered extremist, being an extremist, and he
18 really does pose that dichotomy.

19 Either we give patients full
20 control, come what may, and he actually talks
21 about that a little bit and says that, you
22 know, he doesn't think it's going to be as bad

1 as we all worry about. Or we have a more
2 pragmatic approach, that takes into account
3 everything else that's happening in the health
4 care system, like the fact that you are being
5 measured and paid on the basis of what
6 happens, and that you are held accountable for
7 the decisions that you make.

8 So I think we need to come up with a
9 balance, because otherwise, we're not going to
10 be satisfying the real need in the community
11 for measurement. I mean I think we need to
12 figure out how to do this, and as most things
13 at NQF, we will have to reach consensus
14 through the new term is creative compromise.

15 But I think we need to figure it
16 out, because I don't think we can satisfy
17 both. I don't think we can satisfy the
18 extremist views, which in my heart, you've to
19 read the last paragraphs in Berwick's thing
20 again. He talks about, you know, what he
21 wants when he becomes a patient.

22 I mean nobody could disagree with

1 what he says. I mean it's just -- it's a --
2 it's just obvious that we want a system that
3 responds to us and that treats us with dignity
4 and all the rest. The reality is that we need
5 to find the balance, I think.

6 Not to say that we should not have
7 criteria that include respect and dignity a
8 lot of the things that are here. But I think
9 we need to be realistic about how we can
10 achieve -- how we can move towards this
11 extreme position.

12 MEMBER FIESINGER: I have two
13 thoughts. One is when I was hearing the
14 respect and the compassion, I thought of
15 respect, dignity and compassion of caregivers,
16 meaning selfishly physicians but also nurses.
17 What I see in our residents at our big inner
18 city hospitals is basically the corrosion of
19 empathy. From a first year to a three year
20 they lose it, and it's basically beaten out of
21 them.

22 But that's because you're

1 discharging your patient at the corner of
2 Interstate 59 and Beechnut, because they're
3 homeless. You're discharging the patient with
4 a beautiful plan that you know is irrelevant,
5 and it doesn't matter what you reconcile,
6 because they have no access to health care.

7 You can have all these best
8 practices and measure people on it, but if
9 they know and we know that it doesn't really
10 matter because the system is broken, it's hard
11 for them to maintain that desire to do the
12 right thing. When I talk about we need to
13 look at the big pictures, like yeah right,
14 whatever.

15 So I think -- and certainly I can
16 remember all the time in practice it's Friday
17 afternoon. I'm trying really hard to care
18 about your depression, but I'm sorry, I want
19 to go home, and I wish you had just a strep
20 throat. That's just the reality of
21 physicians' lives, of nurses lives, of
22 everyone's lives, not to be aware of that

1 global context. That's not a measure, but I
2 think an unintended consequence.

3 The second thing is I would like to
4 lump, just because I don't want to more
5 measures. Not that I don't think measurement
6 is valuable, but I thought of what I've been
7 trying to do a lot with patients is apply the
8 motivational idea as much as I can in one
9 minute. What's one thing you could fix about
10 your health? What's one thing you'll do to
11 make that better.

12 Talking about these questions of
13 what is one thing you want us to do
14 differently for you or better for you, and
15 then let's work on doing that might be the way
16 to reduce this. If we can come up with some
17 kind of measure that looks at that, it might
18 be a way to simplify a lot of this, because
19 there are many, many common themes.

20 You know, my son has ADHD. What do
21 we want? We want to not get calls from the
22 school every day. That's what we want. We

1 want him to actually get into college. We
2 don't care about scores. The scores are a
3 means to an end, but our real goal is that,
4 and finding out for each what that is and put
5 it as the chief complaint.

6 CO-CHAIR KOTAGAL: Yeah, Lori.

7 MEMBER FRANK: Thanks. So the
8 vignettes really brought out some of what was
9 discussed earlier today, including by Chris,
10 in terms of taking the systems view, and I
11 would want to make an impassioned plea for
12 incrementalism.

13 I think that even within our group,
14 we have an opportunity here to acknowledge
15 extra system inputs, other health care
16 systems, suspensions on ambulances, the
17 context which many of the vignettes really
18 beautifully brought out, social context,
19 environmental context.

20 So I wouldn't want this group to let
21 go of a goal of including and acknowledging
22 those things that can be controlled within an

1 environment and measured within an
2 environment, and acknowledging those things
3 which can't be completely controlled, but
4 which everyone needs to be overt about, as
5 having important inputs into the outcomes that
6 we're interested in.

7 MEMBER JHINGRAN: A couple of
8 different thoughts. One's very similar to
9 what Lori said and I think Kevin had said it
10 earlier.

11 Even though we're not supposed to be
12 thinking about how to measure the concept and
13 what to measure it with, but it's really
14 important to hone on whether we're thinking at
15 a systems level versus an individual level,
16 because the measure will look very different,
17 or could potentially look different.

18 The other concept which really
19 dawned on me, and I'm not a physician by
20 training, but I'm surrounded by physicians as
21 well as yourselves, is do we include -- there
22 was a lot of element of practice of medicine

1 in many of the vignettes. You know, what to
2 do when, when a scan needs to be done, who the
3 scan is done by, things like that.

4 Is that an element which is part of
5 this what we're trying to measure here. So
6 that's another thing which just dawned on me.
7 Then the last thing is when I heard many of
8 the examples, and of course in our day-to-day
9 lives also, we're dealing with many
10 individuals who are very educated and know
11 what to ask, who to ask, when to ask.

12 Whereas when you look at a
13 socioeconomic status individual, they're
14 pretty lost in our very complicated health
15 care system.

16 So how do you measure that aspect of
17 it, because again, for someone who's very
18 educated and is familiar with the health care
19 system, their -- what good looks like for them
20 is very different than potentially what good
21 looks like for somebody who basically doesn't
22 even have any expectations. They just want to

1 feel better or they have an issue.

2 So that's the aspect which I don't
3 know how to measure, but how do you even
4 incorporate it into the core concepts which
5 we're talking about here.

6 CO-CHAIR KOTAGAL: Raising some good
7 challenges that we have to think about as we
8 go forward. Extremism, how to arrive at the
9 right measure in this context, and then social
10 and economic factors. But it seems like
11 humanistic and empathy came through in all of
12 the vignettes, even through all the technical
13 conversations.

14 MS. PACE: I just want to respond to
15 your question about the medical care, and
16 obviously everyone wants good quality medical
17 care. But I think, you know, we're not going
18 to try to do measures about that. We have,
19 you know, NQF has six or seven hundred
20 endorsed measures, primarily focused on
21 quality and safety, quality, effectiveness and
22 safety.

1 So we really want to, you know,
2 focus our attention on person- and family-
3 centered.

4 CO-CHAIR KOTAGAL: Bruce, I think
5 you're up next.

6 MEMBER LEFF: A very quick comment.
7 You know, we're thinking about patient,
8 person-centered care at the person level.
9 We're dealing about this within systems, and
10 it's entirely possible, I was thinking about
11 Dave's story about waiting for 30 minutes
12 before the doctor comes in.

13 So that person's person-centeredness
14 suffered, but it could very well have been
15 because the physician was with someone, trying
16 to be more person-centered, right. So I don't
17 know if that comes under the construct of
18 unintended consequences or how systems have to
19 deal with integrating all of this. But I just
20 thought it was worth calling out.

21 CO-CHAIR KOTAGAL: You're suggesting
22 that some of our measures could be difficult

1 in part, because of the balance.

2 MEMBER LEFF: Yeah, I think
3 difficult. I think the issue of unintended
4 consequences, the issues of catering to the
5 person versus the, you know, distributive. I
6 guess in an ethical context, this would be
7 distributive justice, right, that kind of
8 thing.

9 CO-CHAIR KOTAGAL: Yes, yes. I am
10 struck by, and this is my own personal
11 observation as I'm listening. I am struck by
12 our need to bring extreme examples to common
13 events, because I feel like what we're being
14 asked to do is to think about what happens
15 every day all the time.

16 But as I listen, I'm often listening
17 to, you know, varications sometimes in asking
18 the question. Is our problem really that this
19 person is more person-centered and came late,
20 or is our problem that 80 percent of the
21 people are sitting in waiting rooms, because
22 physicians don't arrive to the clinic at nine

1 o'clock when the first patient arrives.

2 So just as I'm listening to it, you
3 know, I feel like we're kind of balancing that
4 tension. So Bruce, it's a great comment.
5 Chris, I think you're next.

6 MEMBER LATTS: Or maybe they're not
7 arriving at the clinic. Sorry to break in,
8 but maybe they're not arriving at the clinic
9 because they're trying to be at the hospital
10 when their patients are awake instead of
11 sleeping. It's really complicated.

12 CO-CHAIR KOTAGAL: Point maybe.

13 MEMBER FORREST: Two comments. One
14 is that I like the core concepts, and I
15 thought the commentaries were terrific, and
16 what had occurred to me is that this is
17 ripping a little off from what Bruce said, but
18 these core concepts set up dimensions for
19 measurement, and what we're really talking
20 about is a dimensional approach to measuring
21 person- and family-centered health care, which
22 suggests that (a), there's going to be a

1 spectrum from low to high across each of these
2 dimensions.

3 But (b), those are not orthogonal
4 dimensions. They're inter-correlated
5 dimensions. That actually has implications
6 from a measurement perspective. There are new
7 methods like multi-dimensional IRT that can be
8 used, where you -- if you have information
9 about one dimension, then it actually gives
10 you information about some of the other
11 dimensions.

12 So I just wanted to -- even though
13 we're not going to choose measures, embed this
14 notion that we are really talking about a
15 dimensional approach to assessing person- and
16 family-centered care. The second issue that's
17 very important, both conceptually and from a
18 measurement perspective is the level of
19 measurement, the micro-system level, the viso-
20 system level, the macro-system level.

21 When we think about collaborative
22 arrangements, what is important to understand

1 at the microsystem is really issues around
2 communication and empathy. As you go out to
3 the higher levels of the system, you start
4 talking about infrastructures that support
5 collaboration.

6 So that's another important
7 dimension. So I can almost imagine, you know,
8 the dimensions are rated as columns, and the
9 levels are rated as rows, and the measures
10 that fit into those cells are going to vary.

11 CO-CHAIR KOTAGAL: That's a good
12 point, Chris. Go ahead.

13 MEMBER MACDONALD: Thank you. So
14 everyone probably at this table has a story
15 similar to Troy's, and you go out on 15th
16 Street and stop people going down, and they
17 could tell you exactly the same story. It's
18 just a measure of how completely dysfunctional
19 our health care system is that we're trying to
20 fix.

21 I would just say that having been
22 involved in other NQF things, I'm sort of --

1 I was sort of appalled at the number of
2 measures, the number of process measures
3 especially, that were being developed. It
4 just seemed like an overwhelming. We had to
5 have a measure for everything that you should
6 do, and that we may want to look more at
7 measures of culture, of the organizational
8 culture, rather than specific individual
9 measures about communication.

10 Just the last thing I would say is
11 the measure should be meaningful to patients
12 and consumers. So when we're talking about
13 developing measures, it should be something I
14 understand, you know, as someone who is not a
15 measure developer and not, you know, involved
16 in this kind of research.

17 CO-CHAIR KOTAGAL: That's a really
18 great point, and I wonder, Karen, if you can
19 talk a little bit about the process by which
20 that happens, that the measure is really
21 meaningful to real people.

22 MS. PACE: Right, and I think that -

1 - yeah, it's great. I mean one of the things,
2 and we'll get to in just a moment, as we want
3 to hear from the patient and consumer
4 representatives, but it is something that we
5 specifically addressed when we did our PRO
6 project, that any patient-reported outcome
7 measure that's brought forth, at least to NQF,
8 there should be some discussion about how they
9 determined that that particular outcome was
10 meaningful and valued to patients.

11 So and I think obviously we want to
12 do that with person-centered care measures.
13 We really -- and actually experience with care
14 is one domain of patient-reported outcomes.
15 So we would carry that same thought through,
16 that we would want to identify performance
17 measures that are really going to be
18 meaningful and valued to patients.

19 So that is one of the key questions
20 that we need to keep in mind. I mentioned it
21 earlier. But as we start thinking about
22 performance measures, I think that's a key

1 one.

2 CO-CHAIR KOTAGAL: A caution to keep
3 in mind, a great point. Jen.

4 MEMBER EAMES HUFF: I too want to
5 just echo my thanks and appreciation for all
6 the vignettes that people shared this morning,
7 and starting the discussion with that. I
8 found it really brought out the humanness in
9 health care and the personalness in it, that
10 sometimes gets lost in our conversations when
11 we get to talking about this.

12 It really brought me to a place of
13 being in my heart, you know, of feeling very
14 heart-centered, feeling warm, some of the
15 compassion that was talked about, soft. Then
16 I go to our charge of we're working on
17 performance measures. It's real different
18 juxtaposition of that brings me right up to my
19 head. So how do I reconcile the two of
20 bringing that warmth, that personalness, and
21 the measures, which are very science-based.

22 I think that's a real challenge for

1 us, in terms of looking at what we're doing
2 with this. That brings me to some of the
3 conversations that we get at. They become so
4 science-based, where it focuses more like on
5 the reliability and validity, as opposed to
6 what really is important to being measured and
7 what is important to the patient.

8 So I think that's something for us
9 to keep in mind, as we're looking at doing
10 this work.

11 MS. PACE: And I just want to make
12 one response, is that today, we really will be
13 focusing on what is important to measure and,
14 you know, all the scientific measurement
15 things will come when those measures actually
16 get developed.

17 But the other thing is that, and
18 we'll talk about it a little bit later, is
19 that we don't necessarily have to stay in the
20 box of performance measurement. Kevin
21 challenged us with this idea, and I put some
22 drafts together for you to think about.

1 But is there some of this
2 information that lends itself more to kind of
3 the nutrition label concept of person- and
4 family-centered care? Is there certain types
5 of information that if it were in a standard
6 format, standard definitions that you could
7 look at in a glance, that would give you some
8 sense of at least whether that service matched
9 your preferences, you know.

10 I mean, you know, some of the
11 examples are as simple as do they have
12 extended hours? Do they have evening and
13 weekend hours? Do they, you know, what are
14 the communication methods available? So you
15 know, that's not going to solve everything.
16 I'm just saying that we don't have to
17 necessarily stay in the box of performance
18 measurement.

19 Obviously, there's an interest in if
20 that's possible, what should it look like,
21 what are the things to do. But we do have
22 some flexibility here.

1 CO-CHAIR KOTAGAL: The question,
2 just to clarify. When you say we'll follow
3 the process that NQF follows in the case of
4 person-centered measures, does that go out to
5 a consumer group that then reacts to it, or is
6 it a repeated set of consumer groups? What
7 does that process look like, just for --

8 MS. PACE: Well, basically right
9 now, I mean it would be up to the developer
10 that is actually working on a measure, that we
11 would expect them, as they're developing a
12 measure that's supposed to be on person- and
13 family-centered care, to really do some work
14 with patient and consumer groups, to get that
15 kind of input.

16 CO-CHAIR KOTAGAL: I was thinking,
17 you know, we're not going to say what the
18 measure. We're going to say what we think
19 needs to be measured, and that is about
20 subjective as saying kind of process. So I
21 was wondering whether even that would go
22 through some filter of persons and people who

1 would be able to speak to it.

2 MEMBER LARSEN: I can speak to this
3 a little bit. So the way that the federally
4 funded measure development works is we follow
5 typically something called the measures
6 blueprint, which is something that Medicare
7 puts out. It's a long document about what the
8 government -- when the government funds a
9 contract for measure development, this is what
10 we would want to fund in there.

11 We at the government can change
12 that. We do ask for consumer panels to be
13 part of that measurement group, and for
14 validation with consumers. But so what I
15 would anticipate is as we start looking at
16 more measure development in this important
17 area, we would ask very specifically about
18 here's the recommendations that came from this
19 NQF group. We want you to work on developing
20 measures, you know, using this as part of your
21 marching orders.

22 You know, think about the constructs

1 here. Use this terrific work as the place to
2 start. Then what would happen is an
3 organization that we contract with, so for
4 example Gene does some measure development for
5 federal contracts, would start work on that
6 kind of measure development.

7 He and his team would follow
8 processes, but focused on a specific area. If
9 we said it's waiting time in the waiting room
10 is what we really think needs to be a routine
11 measure of person-centered care, then we would
12 charge a group like Gene's potentially, to go
13 out and start doing that, following a process
14 of analysis, input, public comment.

15 Then eventually, those come to NQF,
16 and NQF is an organization that reviews and
17 brings groups like this together, to do
18 endorsements, to say is that valid or not
19 valid as a measure.

20 CO-CHAIR KOTAGAL: Do you want to --

21 MEMBER deBRONKART: I'll hold off
22 for the panel.

1 CO-CHAIR KOTAGAL: Did I miss
2 somebody here?

3 MEMBER deBRONKART: Yeah, Laurie and
4 Ethan actually.

5 CO-CHAIR KOTAGAL: Ethan and Laurie,
6 I'm sorry. You guys had it up before and I
7 missed you. I'm sorry.

8 MEMBER RADWIN: Okay. So I just --
9 thank you. I wanted to follow up on a couple
10 of the remarks that other people made,
11 Jennifer's remark about her heart being
12 touched. You know, I started out as a
13 qualitative researcher and there are now meta-
14 syntheses of what patients have said makes
15 patient-centered care.

16 And it seems, as I read these, the
17 heart of patient-centered care is really care
18 individualization, and which brings me to
19 something you said, Uma, about the extremes.
20 I think we heard some really good examples of
21 care being highly individualized, with the
22 dilemmas it caused for people like Bruce, and

1 not individualized at all, you know, in the
2 palliative care world.

3 I'm coming to this thinking that
4 care should be individualized enough, getting
5 people out of the situations of emailing some
6 people and writing on their medicine
7 containers for others. You know, the person
8 can tell you when they feel treated like an
9 individual, enough that their care is centered
10 on them, and it doesn't have to be extremes,
11 you know.

12 I'm reminded of what the Picker
13 ended up doing with yes all the time, yes most
14 of the time, and never, and maybe that's the
15 kind of thinking we need to be looking at. I
16 also am aware in my own work, I'm beginning to
17 believe that coordination truly is a separate
18 concept, and to fold it into patient-centered
19 care makes sense, because patient-centered
20 care degrades with poor coordination.

21 Uma, your story of really wonderful
22 coordination, maintaining the patient-

1 centeredness of that young man's care. But
2 it's distinctive, and it's no surprise that
3 there's a whole other panel addressing it. I
4 think we can stay out of that sinkhole, of
5 trying to make our definition include
6 coordination.

7 Lastly, just in terms of families,
8 we did a project in a MICU, at a major
9 academic medical center in Boston, and you
10 want to talk about enough information, too
11 much information, families acting as the
12 proxy, what would the patient want. What does
13 the sister want versus what the daughter
14 wants.

15 I mean there's the paradigm example
16 of how do you individualize care to that
17 person and their family, with the right
18 information and the right choices made? It's
19 a quagmire, and you know, I wonder -- I worry
20 a lot about folding family into patient-
21 centered care, because of what we saw and
22 studied in that highly difficult situation.

1 So that's it.

2 CO-CHAIR KOTAGAL: About the patient
3 and the family and --

4 MEMBER RADWIN: Yeah, yeah.

5 MEMBER WOLFF: I guess just to
6 address your concern about including family in
7 patient-centered care. I couldn't agree more
8 that it is incredibly challenging, because of
9 the heterogeneity in the patient dynamics, and
10 then you overlay heterogeneous family
11 dynamics, and it's not just one family
12 caregiver. There are multiple people who
13 could potentially be involved.

14 But I guess just to respond, I fear
15 leaving family out, because of the important
16 role that they play in a whole range of
17 activities, in terms of navigating the health
18 system, in terms of facilitating self-care, in
19 terms of assuming responsibility and burden.
20 So as messy and as complicated as it is, I am
21 very encouraged that the panel is willing to
22 take some steps towards trying to measure

1 family -- person- and family-centered care.

2 MEMBER RADWIN: Thanks for the
3 opportunity to clarify. I wasn't saying it
4 shouldn't be done at all. In fact, the
5 intervention that we put into the MICU was an
6 early family meeting, within 24 hours of
7 admission, because the family's so important,
8 especially in that situation.

9 So I'm glad you gave me the chance
10 to clarify. It should be there. It's tough.
11 That's all I'm saying. It's challenging. But
12 it needs to be done, and hence that project.

13 CO-CHAIR KOTAGAL: Thank you for
14 your comment. I think in the interest of
15 time, we're going to take Ethan and then Gene,
16 and then I think we have to listen to the
17 patients.

18 MEMBER BASCH: Thank you, briefly.
19 I really liked the anecdotes. They were so
20 interesting and they really -- as a provider
21 and we all, of course, were patients in
22 various contexts, they really resonate. I

1 agree with the comment that there was a lot of
2 overlap within the anecdotes.

3 That doesn't necessarily suggest to
4 me that it's, you know, one big domain or
5 there's co-linearity, but more that really
6 good patient-centered care includes a bunch of
7 different things. To do it really well, you
8 really have to hit them all. If you don't, if
9 one missing, you know, maybe it doesn't quite
10 work.

11 So I'm very about operationalizing.
12 So I was kind of going through and trying to
13 collapse and think about, you know, in the
14 absence of qualitative research, you know,
15 just sort of sitting here thinking about it,
16 to me it really broke down to four major
17 categories, just briefly.

18 Listening to patients, communicating
19 to patients, flexibility of care to the
20 patient context, and finally respect for the
21 patient. So the listening -- so as I think
22 about each of these, and I think you can

1 collapse these pretty nicely into those, for
2 each of them they each pose a very unique
3 measurement challenge, because some of them are
4 more amenable to process measures, others to
5 outcome measures.

6 Different stakeholders are in the
7 best position to report on different aspects
8 of these. To really capture, I think, there
9 may be a necessity for some out of the box
10 tools that, you know, maybe don't -- you know,
11 don't measure quality in the conventional ways
12 that we think about it.

13 You know, I'm reticent to be too
14 prescriptive about how a particular unit
15 should deliver this care. You know, I think
16 there's going to be so much variability even
17 within a provider, within a context.

18 So you know, I think that our
19 challenge is to provide the broader framework,
20 and a way to really kind of get our heads
21 around it. So one more moment? You tell me.
22 It's okay.

1 (Off mic comment.)

2 MEMBER BASCH: So you know, so the
3 first one I said is about listening to
4 patients, which is obviously so important.
5 You know, certainly one can ask patients if
6 they feel that they're being listened to,
7 which is very important.

8 But we know that there are cases of
9 disconnect, and you know, sometimes providers,
10 when you employ these kinds of measures, cry
11 foul and say well, my practice is unique in
12 this way, or you know, look, I've spent the
13 last hour talking to my patient, talking at my
14 patient, talking with my patient.

15 So you know, that's probably not the
16 only metric that we want to use. We may want
17 a process measure around training providers to
18 communicate well and to listen to patients.

19 MS. PACE: Could I just ask you to
20 hold the rest of your thoughts about
21 measurement, until we get to moving on to that
22 section.

1 MEMBER BASCH: Yeah, I'm sorry.

2 MS. PACE: That's okay. I'm glad
3 you're thinking about it.

4 MEMBER BASCH: It's so hard to --

5 MS. PACE: I know, I know.

6 MEMBER BASCH: Yeah, okay. I'll do
7 that.

8 (Simultaneous speaking.)

9 MS. PACE: Okay.

10 CO-CHAIR KOTAGAL: Gene and Annie.
11 Brief comment.

12 MEMBER NELSON: I'm looking at our
13 key question, do the definition and core
14 concepts capture your view of ideal person-
15 and family-centered care? So --

16 MS. PACE: I'm going to ask the
17 patient reps to answer that, but go ahead.

18 MEMBER NELSON: So I -- for the past
19 six months, I've been going to school on
20 emerging models that look extremely promising
21 for better health and better health care, and
22 one of the models is from Sweden. That's the

1 Sweden rheumatology quality registry, which is
2 now being spread to other populations in
3 Sweden.

4 Another is the Improve Care Now
5 Chronic Care Collaborative Network that Peter
6 Margolis and colleagues have developed. If
7 you look at what's emerging in these
8 incredibly powerful, here today but innovative
9 and pragmatic systems, at the center there's
10 the person and family living with their health
11 condition or health state.

12 It could be a family with a newborn,
13 and there's a care team over here, and
14 sometimes they're coming together face to face
15 to virtually, and they have supports
16 sometimes. Like patient-facilitated networks
17 or a clinical learning collaborative.

18 But when they come together, it's
19 for the person to realize better health
20 outcomes that they wish to achieve, mediated
21 by better health care. So at the center of
22 this interaction is this idea, you can call it

1 different terms, but it's co-decision-making,
2 it's co-design my care plan, it's co-
3 production of my health care regimen. IT's me
4 working with, this co working with, in order
5 to achieve best outcomes that I strive for.

6 So in an idealized system, this
7 issue of co-decision-making, co-designing care
8 plans, co-producing the care plans, I think
9 you see in these very progressive and real
10 world examples, getting better results faster,
11 this idea of co.

12 So that's not really on the table so
13 much, but if we think about where we should
14 head, perhaps it should be.

15 MEMBER WALLING: I just wanted to
16 make a really quick comment about -- there was
17 a comment about how residents lose empathy
18 over their residency, and I see that as a
19 motivator for why patient-centered care is
20 really important. I know that I had a lot of
21 existential distress during my training,
22 because I didn't necessarily feel like the

1 team was communicating well with the family
2 and patient.

3 So I feel that if we have a more
4 patient-centered health system, that it will
5 actually improve satisfaction for physicians,
6 as well as patients, because there will be
7 less of that tension.

8 CO-CHAIR KOTAGAL: (off mic) -- that
9 are not patient-centered. They have hard time
10 keeping that. There are some systems that are
11 not patient-centered, you know, have a hard
12 time staying empathic, even though they come
13 in with a desire to be that way.

14 MEMBER MAKAR: I'd just like to say
15 the whole care team, not just physicians. But
16 we have to remember we're talking about the
17 whole care team, right. So it's respiratory
18 therapists, nurses, patients.

19 MEMBER WALLING: Yeah, all care
20 providers. I was just responding to the -- I
21 completely agree.

22 MEMBER BASCH: But I think one of

1 the issues is that, you know, the individual
2 provider may feel very futile if they're not
3 connected to another provider, who can then
4 pick it up and take, you know, take the next
5 steps that are needed.

6 MS. PACE: Okay. But let's move on
7 to our other panel, which we really want to
8 hear from, and then we'll have more time for
9 discussion, and go to the next slide.

10 So we've asked this panel to address
11 the key question, do the definition and core
12 concepts capture your view of ideal person-
13 and family-centered care, and again, we're
14 hearing from our patient and patient consumer
15 representatives. So we'll start with Dave
16 deBronkart.

17 MEMBER deBRONKART: I always like to
18 go last. Well, the thing is there are so many
19 people who have been doing so much good work
20 for so long now, I hate to say something
21 that's stunningly obvious to everyone else.

22 So what I've been trying to do, I

1 mean showing up as a public speaker on this
2 subject several years ago, what I try to do is
3 say something that adds to the conversation.
4 So in my -- what I say, I find myself not
5 actually -- the definition is fine with me,
6 but the question that's always, always bugged
7 me from the beginning of my advocacy, just a
8 few years ago, was so many people have said so
9 many smart things that haven't budged the
10 boulder.

11 FEMALE PARTICIPANT: Right.

12 MEMBER deBRONKART: So I mean I was
13 trained in industry years ago, in system
14 thinking, complex systems, and complex system
15 is the most useful way -- I'm sure many people
16 may be, everyone in this room knows this --
17 the most effective way to think about a
18 complex system is that it's like a mobile with
19 a thousand things hanging from it.

20 Not only are the things all dangling
21 connected to each other, but they've got
22 springs on them of varying strengths. So you

1 have a measure to make sure that Item 147(b)
2 is in this circle. Well, you pull it and
3 everything else moves, right. This is a
4 major, major challenge, especially if we have
5 burdensome ways that clinicians have to spend
6 time documenting that they moved 147(b) into
7 this circle, and the whole thing just doesn't
8 work well.

9 Even the word "outcomes" becomes
10 burdened with well, what did you mean by that
11 and so on. Well and I have -- I have
12 tremendous empathy, and that's why -- I have
13 tremendous empathy for the people who are
14 doing this work, and who are subject to the
15 complications that result, and the unintended
16 outcomes and all of that stuff.

17 I mean I remember many decades ago,
18 when I first had an interest in psychology,
19 somebody, a grad student covertly got
20 ourselves admitted to an asylum, which is what
21 it was called in those days, to document what
22 went on from the patient's perspective.

1 She sat there all day taking notes
2 in her notebook, and when she was -- they then
3 went and looked at what the people who worked
4 there wrote, and what they wrote day after day
5 was "patient engages in writing behavior."
6 Nobody had ever gone to see what she was
7 actually writing, you know.

8 And so this question, what can be
9 said and what can be measured that will make
10 any difference? We also need to understand
11 from the systems perspective, that when -- one
12 thing I learned there is that when you take a
13 complex system and you try to change its
14 direction, and it keeps snapping back, all
15 right, that means sure as you're born, whether
16 you can see them or not, there are feedback
17 loops and forces that have the effect of a
18 gyroscope, which is powerful enough.

19 The gyroscopes are what guided
20 missiles, you know, and we need to -- if the
21 measures we're working on aren't budging
22 things, then we need to call out, with sirens

1 and red flags, hey, everyone who's telling us
2 to do measures, there's something else going
3 on here, and work needs to be done to identify
4 what those forces are, or all this is not
5 going to make any difference, all right.

6 And we have -- I mean I assert that
7 we have a franchise to say this is good stuff,
8 but it's not the only thing that should be
9 measured.

10 The British Medical Journal has
11 started a project now, where they're going to
12 actually have patients as reviewers of certain
13 articles, okay, and they said at the
14 organizing meeting in January, the editor-in-
15 chief, Fiona Godlee, said when we announce
16 this, we must say we are doing this wrong,
17 because we're taking this effort on a
18 volunteer basis from the patient reviewers.
19 In the future, we need to put into our budget
20 to compensate it.

21 So they -- one last thing, a potent
22 vignette on the quality. So to get back to

1 the direct question, in the definition, I just
2 think that it would make sense to put
3 something in, either at the beginning or at
4 the end, that when patient- and family-
5 centered care is happening or is present, all
6 right, the patient and family feel cared for.

7 Because no matter what else is
8 happening with the million things dangling
9 from the mobile, the question is do they feel
10 that they were taken care of, and I've got
11 another vignette for later, but my time's up.

12 MS. PACE: Okay, Joyce.

13 MEMBER DUBOW: So I take the
14 marching orders very seriously, because I
15 think staff has an enormous job. I mean just
16 reading the comments that we provided in
17 response to the first draft, this is going to
18 be a Herculean task, and unfortunately I don't
19 think I'm going to help you.

20 Because I'm going to just provide
21 more ideas. I think what we are trying to do
22 is to describe what a patient wants, and I am

1 prepared for the battles we will have later
2 on, with respect to what the measures will
3 look like.

4 I think we are talking about
5 outcomes. What does a patient want? I don't
6 think we should be touching the processes.
7 Ethan sort of touched on the fact that he's a
8 little bit loathe to identify processes in the
9 measures, and I --

10 In general, if we don't have a good
11 relationship to a known outcome, I think we
12 should stay away from processes, in order to
13 avoid stifling innovation or flexibility and
14 agility with respect to responding to patient
15 needs.

16 So I'm just thinking here about the
17 outcomes that we want to see, and then we're
18 going to have the problem of splitters and
19 lumpers, because I think it was again Ethan
20 who -- but you were talking about more
21 operationalizing, so I'm going to forgive you
22 on that one. I'm an Ethan groupie, so he can

1 do no harm.

2 But I think that in order to be very
3 clear, in order to give very straightforward
4 instruction to those people who are going to
5 be developing these measures, that we should
6 be splitters and not lumpers, because I don't
7 think we want to confuse what we're saying.
8 So with that context --

9 Oh, and the other thing is I think
10 we have to be setting-agnostic. I think we
11 have to take into account that this is going
12 to happen. Of course, the health care
13 setting, not in the acute care setting
14 necessarily.

15 We have to think about the home, the
16 community, inpatient stuff, all the rest of
17 that stuff. So I think we need very
18 straightforward, very explicit statements. So
19 I am not going to wordsmith, but I will just
20 give you an example of what I mean about being
21 straightforward.

22 When it says that my care partners

1 strive to know me, I don't "strive." I want
2 that they know me. That's what I want, and I
3 think we have to read these concepts with that
4 kind of very explicit declarative statement
5 about what we want.

6 FEMALE PARTICIPANT: Well, I'm
7 sorry.

8 MEMBER DUBOW: I think that's what
9 we need.

10 MALE PARTICIPANT: That's good,
11 good.

12 MEMBER DUBOW: So you try, and then
13 we'll see if you do it right. I'm going to
14 skip -- well that's what the measurement is
15 going to be about. We'll determine whether
16 they are achieving what we want.

17 I'm going to skip two and six for a
18 minute. I'll come back to them, because I
19 lump them together. The most important one
20 obviously is the dignity and the compassion.
21 The one about four, where I collaborate in
22 decisions about my care to the extent I

1 desire, or am able to choose the care partner
2 -- oh, this is the one I want to skip.

3 But I think we need to separate out
4 the one, the looking to see whether a
5 caregiver's needs are met, and whether the
6 individual's needs are met. I think that's
7 fundamental, but I think they are separate,
8 because we heard they are different. There's
9 all kinds of literature that tells us that the
10 perspective of the caregiver may not reflect
11 the perspective of the patient, and I think we
12 need to look at it separately.

13 But in so many cases, we know that
14 what happens to the caregiver, in terms of her
15 own capacities to follow instructions, to have
16 the energy, her own health, has an enormous
17 impact on the outcomes of the individual. So
18 I think it has to be separate.

19 I think number six, I would simply
20 say my care partners provide any information
21 I need in a format I prefer, period. I think
22 everything else you've provided reflects an

1 illustration of that. And again, this opens
2 up the recognition that we have to tailor
3 communications to individuals.

4 One size doesn't fit all. We know
5 it, and we need to be -- we need to allow
6 that. But we need to say here's what you need
7 to find out. So as a patient, I want
8 communication about anything in a way that I
9 can use it, that I can understand, that I can
10 act on.

11 The eighth one about communication
12 with and among my care partners, I think, has
13 to be separated. I care about how I'm
14 communicated with. You figure out how you
15 communicate with your colleagues. I want my
16 care to be coordinated. That's not here.

17 I want care that is coordinated.
18 That is a goal that I have as a patient. So
19 I want to see that as an end goal, and I think
20 you should -- any clinician should be able to
21 or should be striving to figure out how to
22 coordinate the care that people need and

1 people will need different types of
2 coordination, depending on the circumstances,
3 depending on the setting, etcetera.

4 So I want the communication with me
5 to be transparent, and you guys want to hide
6 things. Just come up with the results, I
7 don't care. Again, I'm trying to come up with
8 a list of very, very clear objectives. So let
9 me come back to the ones that I find really,
10 really challenging, and those are number two
11 and number four, I guess.

12 Those are challenging for me because
13 they speak to the balance that I was talking
14 about before, in terms of the compromising.
15 I receive the care I need, no more, no less,
16 when, where and how I prefer is going to raise
17 the hackles of purchasers and others who are
18 designing value-based purchasing approaches.

19 People make choices about the system
20 or the plan, but they are making choices that
21 reflect a design. To say that I should be
22 able to get it any way I want ignores the

1 realities of issues around affordability, and
2 the way we pay for services.

3 I think it's a great goal, but I
4 don't see it happening in my lifetime frankly,
5 because I don't think we've tackled the
6 affordability and the cost containment and the
7 cost effectiveness issue. So I see that as a
8 challenge, and the same with the issue around
9 being able to choose the care partner that I
10 want.

11 If you're a member of a team, I mean
12 if you're getting care through a team and a
13 member of the team, it may be that team roles
14 are not decided by every patient, that
15 somebody participates in a team because she
16 represents, she brings certain skills to it.
17 I just think we need to think about what we
18 mean here.

19 Finally in the first one, and I did
20 comment on this, I think we have to have
21 something about my provider knowing me with
22 respect to my spiritual, social life. So

1 there were a lot of comments on that. My
2 financial circumstances.

3 I think the article in yesterday's
4 New York Times about diabetes care and the
5 devices speaks to that. You know the ABIM has
6 stewardship. Part of professionalism is
7 stewardship of resources. We need to grapple
8 with this. Again, in an ideal world, money
9 would not matter. But affordability is
10 absolutely the fundamental barrier to getting
11 good care, and it will impede any effort to be
12 patient-centered.

13 So we have to grapple with it, and I
14 think we need to acknowledge that being good
15 stewards of resources is something that you
16 need to understand my circumstances what I can
17 realistically afford, or maybe help me find
18 places to pay for it. But acknowledge it;
19 it's a need that I have. Thank you.

20 MS. PACE: Okay, thank you.
21 Jennifer.

22 MEMBER EAMES HUFF: So I've

1 completely changed my comments, based on this
2 discussion, when what I thought I was going to
3 be saying for that. But I'll start by saying
4 I think in terms of the core concepts, on
5 talking about those, I think there is what
6 I've heard today some challenge around also
7 meeting our charge around performance
8 measures.

9 I think we just have to recognize
10 that performance measurement is a tool. It's
11 not the only thing that's going to get us to
12 being patient- and family-centered. So it's
13 a tool that we should use wisely and use it
14 appropriately.

15 I think that speaks to not having a
16 plethora of measures or lots of measures that
17 aren't high value, and that also means we may
18 not be getting concepts that are really
19 important to patient-centeredness, like how to
20 --

21 I think culture. There are ways
22 that you could get at that in measurement, but

1 there are ways that you can't. So what is it
2 that we can within the realm of performance
3 measurement. So that's my introductory. So
4 I was, like I said, inspired by the vignettes,
5 so I'm going to add my own, that sort of
6 illustrate some of my comments on the core
7 concepts.

8 So the first is I'm going to talk
9 about the birth of my first son, who's four
10 and a half, and I decided I wanted to have a
11 midwife and have my birth at a free-standing
12 birth center. I did this after talking with
13 my OB/GYN and asking her what her C-section
14 rate was, and pretty much almost getting the
15 cold shoulder from that, and really insulted
16 that I asked her that.

17 When I did tell her, after having
18 many conversations about our care, that I was
19 deciding to go to a birthing center, she left
20 the room and did not come and talk to me
21 anymore, and sent in her assistant to talk
22 with me.

1 So at the birth center, my first
2 appointment was two hours long, and that
3 wasn't just my first appointment. Every
4 appointment at the birth center was two hours
5 long. It wasn't the ten minutes. One of the
6 things they did is they did a lot of patient
7 education on that, which I didn't get
8 previously.

9 They did a lot of social-emotional,
10 asking me about my home life and what that's
11 like, you know, incorporating a lot of things
12 in that. Ultimately, though, it came that I
13 could not deliver my child at the birth
14 center. I became a high risk patient, and was
15 transferred to an academic medical center.

16 Yea! So we're talking about
17 extremes. You know, here I have the extremes
18 of care, and it was clear that the academic
19 medical center really wanted me to have a C-
20 section right from being admitted, and that
21 was sort of the atmosphere that was pretty
22 much given.

1 It was also clear they were sort of
2 -- they were giving me a little bit of time,
3 but they were waiting until the next shift,
4 where the next shift would have to tell me the
5 decision. The next shift started on July 1st,
6 yes. So you look at the two differences.

7 So a couple of things around this.
8 The importance of number one, of knowing me as
9 a whole person and the things that are
10 important to me was clearly exemplified by the
11 birth center and the midwife, and wasn't felt
12 in the other, and I think there are ways of
13 measuring that.

14 I will say, you know, at the
15 academic medical center, they were nice to me,
16 you know. They treated me -- they were
17 friendly and stuff, you know. It wasn't that
18 they were that rude.

19 But I felt like my birth center and
20 being there, my care team was my family, you
21 know. There's a difference. I wasn't just a
22 partner; I was a family, and I was in my home,

1 you know, when it came to that. At the other
2 place, I felt like a guest and a visitor, you
3 know. It was a really different atmosphere.
4 So you get some of the niceness.

5 I think the only way you're going to
6 know that is by asking me, you know. I think
7 that comes out in the importance of patient,
8 person, family-centered care, of really going
9 to the person that's receiving the care or the
10 family and asking them. So that is that.

11 So with my second child, who's eight
12 months old, which explains why I leave every
13 so often. So I do apologize for that, I tried
14 to find a midwife with my insurance. So there
15 were four midwives that were allowed under my
16 insurance with a particular hospital. There
17 are only four midwives at one hospital in the
18 area. There weren't midwives at other
19 hospitals.

20 This hospital is known as the baby
21 mill. So four midwives to actually treat a
22 very large metropolitan area. So two were

1 busy, one was going on vacation, so I didn't
2 get a midwife. I stuck with my OB/GYN, which
3 was different from the first one, and I had a
4 nice relationship with her, and I did feel
5 like she would really respect my wishes and
6 she did a lot of things.

7 I also wanted to have the connection
8 with the doctor, because I was going to be
9 doing a VBAC, and that was really important to
10 me. To find out where I wanted to go for a
11 VBAC yes, the place does a VBAC or no, which
12 is what is currently publicly reported was
13 very unsatisfying, you know.

14 So I did go around and ask and get
15 insider information on VBAC rates, and the
16 hospital I did end up choosing actually in
17 their classes do share that information, and
18 they're well-known for having really high VBAC
19 rates. I think that's a place where culture
20 comes in, you know, culture and outcome. I
21 think that's some of that can be reflected in
22 the measurement.

1 I will say with my OB/GYN, I learned
2 to get the first appointment after lunch or
3 the very first appointment in the morning. I
4 would have waits of at least 45 minutes or an
5 hour for a ten minute appointment. So I think
6 that goes to the respecting my time. I'm
7 forgetting which one that is, seven. That's
8 a really, you know, and using it efficiently
9 becomes really important.

10 And I also did feel like with that
11 one very collaborative in the decisions,
12 because there were other physicians in the
13 practice that did not agree with my choices,
14 and my doctor wrote it everywhere, made it
15 known. So it didn't matter what physician I
16 was getting; my choices were going to be
17 respected.

18 Four and seven. So in that
19 instance, the outcomes were really important
20 to me and knowing that information. I learned
21 that I wrote a lot on my previous experience,
22 of my education that I got from my first

1 birth. I didn't need as much as my second
2 birth.

3 So I didn't get that as much, you
4 know, with my doctor. It's pretty much you go
5 to the hospital, you have your class. But it
6 wasn't as needed, so the flexibility around
7 that was fine. The other thing I will say on
8 this is trying to figure out how much this was
9 going to cost me was really complicated.

10 At the time I had a PPO, so when I
11 first tried to go to nurse midwives, they're
12 out of network, and it took me multiple calls
13 with the health plan to even figure out --
14 first, they don't readily tell you midwives,
15 you know, and sort of pushing on that, and
16 then trying to figure out how much all of this
17 is going to cost me out of pocket in advance,
18 because we know what the care in general is
19 going to look like, if it's normal.

20 I have concerns about the cost being
21 just related to the care partners providing
22 the information, because that was something if

1 you're an insured patient, really the role of
2 the health plan, and I don't know if we're
3 looking at health plans as care partners in
4 this context.

5 But I do think per Joyce's comments,
6 affordability, how much things cost, that's
7 really important to patients now, as we're
8 taking on, you know, high deductible health
9 plans, greater burden of the share, having
10 more of that reflected in these. It felt like
11 that was really hidden in the core concepts.

12 Lastly, I'll say my mom had surgery
13 at 9:00 a.m. this morning. She was having
14 surgery because she had fallen two months ago
15 and broken her arm, and they found out for
16 days ago they missed one of her breaks, and
17 that was why she was in a lot of pain.

18 I don't think there was anything in
19 here that would have gotten at that being sort
20 of the right care, that she wanted to get all
21 the breaks. So again, I think that reflects
22 going back to the patients. I think it's

1 different than some of the other events, you
2 know.

3 I have an uncle that a sponge was
4 left in him and I think, you know, objects
5 left in the body is a never event and that
6 turns into a measure. So there are ways some
7 of that is captured, but there are ways in
8 which some of it isn't. So asking the
9 patients again becomes really important.

10 Then I'll just end with saying I
11 think there are a lot of words in the core
12 concepts, and I'm missing the heart and
13 feeling in it. If we're really looking at
14 talking from a person-patient sort of family
15 point of view, this reads a little bit
16 academic to me.

17 So how we can massage it, and also
18 simplifying it. I'm struck by we've had the
19 concept of right care, right time, right
20 price. Very simple, you know what it is, and
21 it is reflected in a lot of these things, but
22 with a lot less words. So there may be a way

1 to incorporate that concept, and build on a
2 few things around the whole person, whether or
3 not you sort of consider that right care.

4 But it just -- that felt, that keeps
5 coming back to me. That's really simple.
6 That gets at a lot of what patients are trying
7 to get at.

8 MS. PACE: Right, and I think that's
9 a conversation we'll have to have about the
10 overlap in other quality domains, because
11 affordability, you know, getting the right
12 care at the right time is part of getting
13 effective care. So obviously patients want
14 that, and it is trying to find the balance of
15 where we put our scope, I think. Yeah, that's
16 good.

17 MEMBER BASCH: Can I make a quick
18 comment? Just a question for you. So you
19 know, if you maybe went to providers who maybe
20 don't think about -- I mean they think about
21 these things, but maybe not operationally.

22 You know, one might say okay, you

1 know it's one thing to implement patient-
2 centered, let's say processes in order to
3 improve the kinds of outcomes that providers
4 think about, right, which are like, you know,
5 for example team-based care for young people
6 with asthma, where actually, you know, they're
7 hospitalized, let's say a few exacerbations,
8 they have improved quality of life.

9 But maybe another thing to implement
10 measures to improve your happiness with, you
11 know, with your care, with your experience.
12 Actually, my wife and I had very similar
13 experiences to you with the births of both of
14 our kids. We tried two different institutions
15 and neither really gave us what we were hoping
16 for.

17 My wife and I actually this
18 conversation many times, which is you know,
19 well let's say that, you know, we had gone to
20 a birthing center and been able to do that and
21 gotten all of these things, you know.

22 Was it actually our preference to

1 get better outcomes, because we were at a
2 tertiary care center, where you know, they
3 treated us terribly, but you know, we had
4 healthy children, versus you know, we felt
5 really good about our experience and it was in
6 line with our values, but you know, maybe it
7 didn't actually affect the health outcomes?

8 One could argue that this sort of
9 getting the kind of care that I want in the
10 setting that I want actually is affecting
11 meaningful outcomes, because you know, as a
12 parent you're more comfortable.

13 You can serve the needs of your
14 kids or you have more information. But you
15 know, I think to a lot of providers, that's a
16 squirrelier, if you know what I mean. How
17 would you distinguish, you know, the two?

18 MEMBER EAMES HUFF: Yeah. So I'm
19 going to say even though I ultimately got
20 better outcomes with going to the academic
21 health center, I think that was built on what
22 was done with the birth center. So the birth

1 center -- I changed my eating habits, because
2 they sat down and talked with me, and went
3 through that. I would not have done that with
4 my doctor.

5 I changed the way I -- how much
6 water I drank, because of the measure. I
7 don't think my doctor would have done it. So
8 I think, even though the ultimate outcome was
9 really good, I think the patient engagement
10 throughout the process that I had with the
11 birth center was really important to the
12 ultimate outcomes, and it actually became
13 something that they couldn't control, in terms
14 of why I had to get transferred.

15 To the other point of some of the
16 processes of care versus the outcomes, you
17 know, of getting the right care, sometimes you
18 want that, even though it's not the warm and
19 fuzzy care, you know, the healthy baby in the
20 end, right, you know.

21 So people will tell me, forget about
22 the care; you have the healthy basis, and

1 yeah, it is important.

2 MEMBER BASCH: Surgeons don't have
3 to be nice.

4 MEMBER EAMES HUFF: Right. It is
5 important to have the healthy baby, but I
6 think I'd go back to your concept of what you
7 said, when you were saying there were multiple
8 domains and the importance of doing well in
9 all of them, you know. So while the right
10 care is really important, also treating me
11 like I'm a person is really important.

12 You can weigh them a little
13 differently, but to get person-centered care,
14 it's doing all of them.

15 CO-CHAIR KOTAGAL: Good. I think on
16 that note, we have three more people to
17 present, so I think we're going to go to Mary
18 next, I think. Mary?

19 MEMBER deBRONKART: Excuse me. I
20 had appointments during lunch. So we have an
21 estimate of when we're going to be doing lunch
22 now?

1 MS. PACE: We're still going to
2 break for lunch at 12:45.

3 MEMBER deBRONKART: Oh we are?
4 Okay.

5 MS. PACE: Yeah, and then we'll come
6 back and finish this discussion. We've kind
7 of spent -- we'll break for a half hour for
8 people to get their lunch, and can bring their
9 lunch back if they're not finished. But then
10 we'll resume and continue our discussion.

11 MEMBER MACDONALD: Thank you. Good
12 comments, and I'll try and be brief, and I
13 appreciate that Joyce was so on task, and I
14 agree with almost everything that she said.
15 I certainly would take "strive" out of the
16 first one, and number five, my family care
17 partners include those I choose. They'd
18 better include those I choose. It would be a
19 very strange situation that they didn't
20 include those I choose.

21 But I wanted to say one thing about
22 number eight, the care coordination and the

1 communication thing, which is I think
2 somewhere in here there has to be who is
3 responsible for communicating with me. Who is
4 ultimately responsible for primary
5 communication with me, and like everyone else,
6 I'll do a quick example.

7 My brother had depression, diabetes,
8 Parkinsonism, then got cancer. You know, he
9 called me and he said you know, I have all
10 these different doctors, but he's in tears,
11 because he's like who's telling me what to do?
12 Who's supposed to be telling me what to do?

13 It was not clear to him. I think
14 the primary care doctor, I'm not sure, you
15 know. Then he went back and forth between
16 hospice and hospital and it was different
17 people all around. So you know, when he died,
18 he was delirious, because his meds were wrong,
19 because there were too many doctors and they
20 weren't recognizing. You know, this is not an
21 unusual story.

22 There needs to be someone who's --

1 for it to be patient-centered, who I
2 understand is the person who's responsible
3 ultimately for my care, you know, and the
4 person that I will talk to and the person will
5 explain it to me.

6 So I don't know if that's like a
7 structural measure, and I wonder if some of
8 these things that we should be thinking about
9 are more structural measures. My mother died
10 in pain because it was lunch, and the nurse,
11 you know, one of the nurses was gone from the
12 unit. So I couldn't get the pain meds that I
13 needed, because she was busy with something
14 else.

15 So some of these things might be
16 kind of structural measures. I would be very
17 -- I look at these concepts, and I think the
18 measures are probably going to end up being
19 patient survey kind of measures, what was your
20 experience.

21 I would just be cautious about using
22 those kinds of measures, having just filled

1 out an HCAHPS myself, with the surgery, you
2 know, with some surgery I had a couple of
3 years ago.

4 I didn't want to get anyone in
5 trouble, you know. I sort of remembered what
6 happened, and the questions didn't really hit
7 the experiences that I had that didn't -- that
8 were bad during that thing. They didn't
9 really fall into that domain.

10 So I would be kind of cautious about
11 relying entirely on patient surveys and
12 patient reports, and try and find more
13 structural measures, outcome measures. I'm a
14 little cautious about process measures as
15 well, because they can be just sort of check
16 the box, you know.

17 I took a class in this so it's done.
18 I took a class in this and it doesn't really
19 relate to whether the culture has changed.

20 I just finally go back to Dave's
21 point, that we've been trying to do this for
22 how long now, you know, and maybe we have to

1 be a little more prescriptive, and maybe we
2 have to be a little bit more concrete, you
3 know, and what we're saying has to happen in
4 order for that change to occur.

5 MEMBER CONNOR: Hearing all of these
6 wonderful vignettes just reinforced that
7 systems matter, and they matter a lot.
8 Hearing Gene's wonderful description of the
9 care provided to that young woman, versus
10 Troy's thought on a late Friday, when he's
11 tired, anxious to go home, and someone has a
12 long list of issues that they want to discuss.

13 So when we consider, you know, the
14 measures, and I know this isn't so much about
15 the measures right now, but I do think we have
16 to consider what we're really going to be
17 looking at.

18 The other thing that Gene pointed
19 out was even though he was addressing number
20 one in terms of the core concepts, he also
21 nicely described "I received the care, no
22 more, no less, when, where and how I prefer,"

1 and actually I'd like to receive my health
2 care in that center you described to us, but
3 I'd like a health coach.

4 The other thing when I think about
5 systems again, and this probably goes back to
6 all of my work in patient safety, where I
7 investigated a multitude of medical errors, it
8 makes me think of another good example, a
9 simple example, where you may have an
10 interpreter.

11 Here, you're going to be meeting
12 your patient and family needs by having
13 someone who can translate the language for
14 them, and it's not aligned, because the
15 interpreter shows up on time. The patient and
16 family may be delayed, and the physician has
17 fallen behind on seeing his or her clinic
18 patients that day. So again, it's a systems
19 issue.

20 The other point I wanted to make was
21 related to fear of partnering with care
22 partners. There's a great fear within the

1 medical community, and I have heard this many
2 times. "Well, you know, the families, the
3 patients, they're going to take over, and we
4 won't be able to carry out the care we need to
5 deliver."

6 This is huge, absolutely huge in the
7 medical community, from all of the various
8 hospitals I worked with. So what I think I'd
9 like to convey here, and hopefully it's
10 conveyed in some of the language around
11 partnerships, is that a partnership is a
12 partnership.

13 It doesn't mean that the patient and
14 family necessarily have carte blanche with
15 whatever they want. The clinicians are able
16 to deliver care in a way that they feel is
17 important too. So it's a coming together of
18 the patient, family and the clinician for the
19 care encounter.

20 The other point that was made
21 related to the emails and difficulties with
22 those, patients choosing multiple care

1 partners. There are systems ways, in some
2 respects, you can get around this, by having
3 family meetings structured so they occur
4 sooner. You have the right people in the
5 room. The family understands the purpose of
6 the family meeting and their role in that
7 meeting. So just some other suggestions
8 there.

9 The other thing I'd like to point
10 out is what we're seeing families are the
11 stewards of patient safety. How many of you
12 have been with a family member or a loved one
13 or a friend, when you have actually prevented
14 a medical error? I know I have. Okay. I see
15 many heads acknowledging that point.

16 So when we think about partnerships
17 and including the family, I think that's just
18 an important point to consider. I loved the
19 point, I think Dave you made, about the
20 clinician tweeting patients when he or she was
21 going to be delayed. I think all of this work
22 calls for the opportunity to innovate and

1 innovate well.

2 MEMBER deBRONKART: It's not very
3 expensive.

4 MEMBER CONNOR: Hmm?

5 MEMBER deBRONKART: It's not very
6 expensive.

7 MEMBER CONNOR: Right, right. And
8 then thinking about the 30 year-old patient,
9 whose family didn't want to adhere to the diet
10 that was prescribed for him.

11 You know, when we think about team-
12 based care, and I think there have been some
13 fine examples of that, one opportunity would
14 have been to meet with the nutritionist
15 sooner, if we're thinking about team-based
16 care, and really think about using a strength-
17 based approach with this family, so they feel
18 that their knowledge is being acknowledged,
19 and that they can control the situation from
20 that perspective.

21 My last comment relates to the core
22 concepts. My first inclination was why are

1 they so long, why are they so wordy, and then
2 I did back off a bit. I thought well, maybe
3 we need this level of precision, since we are
4 going to ultimately come up with measures for
5 person- and family-centered care.

6 But it reminds me of the work done
7 by the Institute for Patient and Family-
8 Centered Care that initially started off with
9 a much longer list, and then distilled that
10 into the four core concepts that I think most
11 of you are aware of, and you can even distill
12 those four concepts into four words:
13 collaboration, participation, information-
14 sharing and respect and dignity. That's
15 something that most people are able to
16 remember.

17 My very last comment is the last
18 point about communication with and among my
19 care partners. I think transitions of care is
20 a huge, huge problem in health care, and I
21 sort of liked seeing that this included "among
22 my care partners," because if they're not

1 communicating effectively, and there are
2 enormous problems with this, there is no way
3 that a clinician can communicate effectively
4 with a patient and family. So another issue
5 to point out. Thank you.

6 MS. PACE: Okay, Sally.

7 CO-CHAIR OKUN: Okay, thank you. I
8 realize I'm between now you and lunch, and
9 Dave's commitment.

10 So there's so much has been said
11 already, but I also want to acknowledge just
12 how powerful the vignettes were, and how I am
13 continually impressed by just how powerful any
14 story related to anything related to health,
15 in any way at all, is always powerful, and
16 helps to move and innovate us in ways that we
17 need to challenge ourselves. I think that's
18 just one really important piece to always
19 remember.

20 I'm not going to go into each of the
21 things where I might have a comment. I'm
22 going to talk broadly, and what I see missing

1 here, although I think there's a lot of really
2 good stuff, is sort of a lack of attention to
3 the preparedness that we need to give to
4 individual people to become patients.

5 So I think what we've done is we've
6 defined what patient and family -- person- and
7 family-centered care could look like when
8 you're a patient. But I think what we've done
9 is sort of taken people off the hook from
10 being somewhat prepared, to engage in being a
11 patient.

12 So I'd like to sort of challenge us
13 to think about that. I do think there are
14 ways to do that, and I certainly take that
15 into consideration. Some people will be too
16 vulnerable for that, but yet some members of
17 the team need to then step up and say well,
18 they are too vulnerable in this situation. So
19 we need to start thinking about how we can be
20 their champion for what they might need.

21 So I'm sort of always impressed by
22 something I did about 10 or 12 years ago in a

1 community-based project we worked on, and we
2 came away with the ultimate statement. As we
3 tried to integrate this type of care across
4 one county in Massachusetts, and it was that
5 living well, whether I'm well, ill, care-
6 giving, whether I'm experiencing complicated
7 aging, requires creative collaboration across
8 all the communities that touch me, that all
9 the communities that touch my life are going
10 to have to have some role in my ability to
11 live as well as possible.

12 Now I'm the only person who knows
13 what all of those communities are on some
14 level, right? So I think what we're lacking
15 here is some way of being able to have an
16 internalized mechanism for gathering that
17 information in a systematic way, from real
18 people about what their real lives are about,
19 and then being able to integrate that into the
20 patient's person- and family-centered notion
21 of what care can look like.

22 So the other thing, as you know, I

1 come from PatientsLikeMe, and we have over
2 250,000 patients today sharing and learning
3 from each other, and that's a network that
4 actually is just another community, and we
5 have to think about how we're integrating
6 these novel environments.

7 But one statement that we use that I
8 think is really important and just is really
9 powerful, and can help us begin to think about
10 how do we help people, individuals, begin to
11 understand that they may at some point need to
12 encounter the health care system.

13 It could be that that happens over
14 time chronically, or it could be that it
15 happens rapidly in a bike accident. There are
16 different ways that you encounter it.

17 But at any point in time, I think if
18 we ask ourselves this question honestly, even
19 if it we ask it of ourselves today, given my
20 status, so that means how am I doing today?
21 Am I well? Do I live with a chronic illness?
22 Is there something I need to be considering?

1 What's the best outcome I can hope to achieve?

2 So hope means I'm not asking for the
3 moon. I'm asking for what's possible within
4 the confines of what we've got available, and
5 how am I going to get there. That's the
6 fundamental question we have built
7 PatientsLikeMe upon.

8 It's sort of saying as a person who
9 knows what my assets and strengths and gaps
10 and vulnerabilities are, what can I hope to
11 achieve based on how I'm doing today, and how
12 the heck am I going to get there, and who's
13 going to help me do that?

14 So I think what's what I think is
15 just missing somewhat fundamentally from what
16 we've done. I think frankly it's interesting
17 to me, because I think what we've done is
18 we've taken person and family-centered care
19 and made the concepts a bit provider-centric,
20 because they're all about what you're going to
21 be doing for me, and actually I think what we
22 need to do is flip it slightly and say whoa,

1 you know, I need to do something too.

2 FEMALE PARTICIPANT: Can we take a
3 break?

4 MS. PACE: Yes. I think it's time
5 for our break and lunch, and so we will
6 reconvene at 1:15. So we'll, you know, if you
7 want to, bring your lunch and drinks to the
8 table. But I'll give you a little bit of a
9 break. Than you all. Very good discussion,
10 very provocative. Thank you.

11 (Whereupon, the above-entitled
12 matter went off the record at 12:47 p.m. and
13 resumed at 1:15 p.m.)
14
15
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21
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1:15 p.m.

You each -- we need to have them give you the individual receipt and you pay for it and then submit for reimbursement to NQF. That's the way we have to do it with our contracting and accounting here.

MEMBER GHAZINOUR: Yes. So the restaurant is called Mayo Restaurant, and I

1 can print the direction to the restaurant for
2 you. It's for 6:30 p.m. tonight, and the
3 reservation is for 20 people, and I think we
4 have 16 or 17. So we have three additional
5 spaces, if anybody would like to join the
6 group.

7 (Off mic comment.)

8 MEMBER GHAZINOUR: Yes, I can take
9 your name.

10 MS. PACE: But you're saying we have
11 a big enough -- we have enough space for the
12 entire committee to go, if they chose to.

13 (Off mic comment.)

14 MEMBER GHAZINOUR: Yes, yes. Her
15 group is included. Sure, okay.

16 MS. PACE: Okay. So Mitra will
17 print that out. We'll meet there at 6:30 or
18 before, if you get there earlier, and look
19 forward to continuing our discussions, I'm
20 sure. Do you need -- you don't really need
21 names or additional information?

22 MEMBER GHAZINOUR: No.

1 Public Comment

2 MS. PACE: Okay, all right. So this
3 is the time that we set aside, to see if there
4 were any public comments from anyone here in
5 the room or on the webinar, and I know we just
6 have a small audience contingent. But I will
7 ask the operator, do you want to see if anyone
8 on the phone would like to make a comment?

9 OPERATOR: At this time, if you
10 would like to make a comment, please press
11 star, then the number one on your telephone
12 keypad.

13 (No response.)

14 OPERATOR: At this time, there are
15 no public comments on the phone line.

16 MS. PACE: And Kaitlynn, what about
17 on the webinar? Any chat?

18 KAITLYNN: No.

19 MS. PACE: Okay, and anyone here in
20 the room?

21 (No response.)

22 Definition and Core Concepts

1 MS. PACE: All right, okay. Well,
2 we will pick up the next agenda item then,
3 which is actually to spend just a few more
4 minutes to tie up our -- finish or continue
5 our discussion about the definition and core
6 concepts. Let me just explain a little bit
7 about what we're going to do the rest of the
8 afternoon, just to put this in context.

9 So we wanted to, because we knew
10 that we had to break for lunch at a reasonable
11 lunch time, but probably if people still a few
12 more comments to make about the definition and
13 core concepts. So we want to finish that up,
14 and then I'm going to spend a little bit of
15 time talking about measurement framework, to
16 prepare us for the afternoon small group
17 discussion.

18 Before we go into small group
19 discussion, we're going to have a couple of
20 presentations by webinar and conference call
21 on just some innovative ideas that are
22 happening, just to again stimulate some

1 thinking before we go into our small groups.

2 We will then go into small groups,
3 where -- and we have given you an assignment.
4 Hopefully it's okay with everyone, but it's in
5 your packet, and there's a sheet that looks
6 like this, and there's some instructions.

7 But I will go over those with you
8 when I talk about the measurement framework,
9 just to give you -- and there will be a staff
10 person in each group, and you'll have one of
11 your own committee members that will be your
12 facilitator. But we will go over that again.

13 Then we'll see how we're doing on
14 time. We may not come back to report out at
15 the end of the day, if we need that time in
16 your small groups, and may defer that to
17 tomorrow morning.

18 So we intentionally had worked out
19 several plans, to see how it was going and
20 where we needed the time. So we'll cross that
21 bridge when we get to it, but for now, why
22 don't we see if there are any further

1 comments, and I'd like to take this maybe
2 until 1:30, and then we'll resume, and then
3 I'll jump in with the measure framework.

4 But if there any additional
5 comments, questions, suggestions regarding the
6 definition and core concepts?

7 CO-CHAIR OKUN: I just would like to
8 bring our attention to the line here, because
9 I think this is important, before we go into
10 the small groups.

11 For anybody who identifies something
12 that they feel strongly about, they feel like
13 that you know it would prevent them from
14 moving forward for some reason, anything on
15 the information or the definitions or the core
16 concepts, it would be helpful, I think, for us
17 to just talk about those somewhat now, and
18 then as we go into the small groups, we all
19 have some awareness of people's perspectives
20 on that. So just throwing that out.

21 MS. PACE: I'll just also just one
22 other thing. I'll acknowledge we have heard

1 your suggestions, and you know, we can --
2 we'll continue to kind of mull those over.
3 But I think as Sally mentioned, before we go
4 into the groups, we want to find out if there
5 are any strong objections to anything that we
6 have to take into account.

7 But we'll continue to be working
8 through these, as we continue our work.

9 MEMBER LARSEN: You know, one thing
10 that I heard us talk about, that I don't
11 necessarily see in here is that I think I
12 heard that person- and family-centered care
13 is a system attribute, not just an individual
14 personal attribute.

15 I don't know if that rises to the
16 level of one of these attributes or our
17 definition, but you know, in many of the
18 conversations I've had with people around,
19 there's this tension between our measurement
20 that's always focused on a person, an
21 individual clinician, versus how we're
22 thinking that it's very difficult for any one

1 clinician to make this happen as an island.

2 MEMBER MAKAR: I have a comment.

3 One of my questions is in regards to how this
4 is ordered, because I feel that the
5 coordinated care and transitions of care is
6 really huge, and I didn't know if these were
7 ordered. So I would ask the group to think
8 about, you know priority order of them, if
9 there is one.

10 Then the other issue was with number
11 five. I understand the rationale to say "care
12 partners," but I just think number five could
13 be confusing with care partners and other care
14 partners. Then lastly, it's about information
15 being thorough and comprehensive, and not
16 omitting key pieces.

17 So I guess what that gets to is very
18 often, and we're trying to operationalize
19 something in an antiquated system. But we're
20 trying to apply this to what we have today,
21 and also be future-thinking. I think what
22 happens is you tend to think of your own

1 space, because it's overwhelming to think of
2 the continuum, and there has to kind of be a
3 way to tie that in.

4 So the example that Jennifer was
5 giving about the fact that she felt her
6 midwife was really patient-centered. It just
7 struck me that if they truly were, they would
8 have been thinking about the high risk
9 patients that then had to go to the AMC,
10 academic medical center.

11 But that was a portion that they
12 really weren't thinking about, because she was
13 kind of on her own to deal with that. So it's
14 a concept I just want to throw out there.

15 MS. PACE: And I think just I'd like
16 to hear other comments about the care
17 coordination. The way that last core concept
18 is currently framed, it's really about the
19 communication, and we know, you know, we've
20 had some discussion earlier about care
21 coordination being a very big topic on its
22 own, and I know we've had another project on

1 that.

2 So I guess, you know, I'd like to
3 hear whether -- how you guys view that,
4 whether care coordination is under person- and
5 family-centered care, if it's another domain
6 and, you know, obviously they're related. So
7 that may be something to have a little
8 discussion about.

9 MEMBER FIESINGER: Okay. I'll give
10 you a quick comment on that, and then say what
11 I was going to say. So coordination is very
12 important. What I think is as a provider, if
13 we're already -- coordination is dealt with
14 elsewhere. That's fine with me. This could
15 focus on communication, so get it
16 coordination.

17 Meaning I struggle to get notes back
18 from consultants, far maybe 90 percent of the
19 time. So patients assume we all talk. So
20 they assume I'm already doing it. The dirty
21 reality is that I'm not. I think if we
22 measured and pushed communication, a fair

1 amount of coordination will follow. Not
2 enough.

3 Then my comment I was going to make
4 before is just I know we're not doing
5 measures, but as much as our concepts can
6 focus on creating things that are actionable,
7 that I and the patient can see, because
8 certainly what frustrated physicians, when I'm
9 talking to physicians, trying to motivate
10 them, is if they put forth a lot of effort and
11 can't see any change, their first reaction is
12 what's the point, and then you're frustrated
13 and then enthusiasm drops.

14 So I think that's true for support
15 staff, and I'd love to get granular and go to
16 the nitty-gritty. But when I'm thinking about
17 me in the room, trying to do something,
18 something that's lumped together helps, and if
19 it's something simple as "Was this visit good
20 for you?" Okay, it wasn't. Can you tell me
21 why? What's one thing you would have us
22 change. Okay, great.

1 Because I did that with our
2 residents. One resident said lectures are an
3 hour. I'd like to have 30 minutes, so I can
4 keep up on my charts. Great, because I'd
5 rather not talk to you an hour. I can tell
6 you're doing your charts when I talk to you.
7 That was very helpful, and we can take action
8 on it.

9 MEMBER RADWIN: I may be repeating
10 myself here, but you can't have good patient-
11 centered care without coordination. But the
12 interventions to improve coordination are
13 different than the interventions to improve
14 patient-centeredness.

15 You know, I'm currently hoping to be
16 testing on a model that looks at patient-
17 centered care before transition and its
18 related outcomes, patient-centered care after
19 transition and its related outcomes, and the
20 coordination activities that affected the
21 amelioration or degradation of patient-
22 centered care in that second setting.

1 And you really can distinctively
2 measure coordination activities that are
3 different, but influence patient-centered
4 care. So communications is quite a bit
5 different in some ways than coordination, in
6 terms of how it's operationalized.

7 MS. PACE: Jennifer.

8 MEMBER WOLFF: So I guess I have a
9 question, which has to do with how important
10 it is to sort of tease out individual core
11 concepts, and sort of split them individually,
12 versus recognize that there is some overlap
13 across these, and attempt to come up with core
14 concepts that are more parsimonious, and I
15 guess I'm wondering if you, Karen or others at
16 NQF, could give us some direction, so that we
17 can reflect on what our goal is in the
18 afternoon activities?

19 Then the other comment that I had is
20 going back to some comments that Sally has
21 made a couple of different times, about the
22 patient being part of the care team, and

1 potentially this notion of preparedness as
2 being something that may not be present in
3 these concepts that have been numbered.

4 MS. PACE: Right. So I'll take part
5 of that, and then Sally may want to add to it,
6 and I think Gene mentioned this as well. In
7 the second bullet point of number six about
8 confidence and capacity to care for myself.
9 I don't know if that encompasses, Sally, what
10 you were talking about, of preparing to be a
11 patient or participant.

12 CO-CHAIR OKUN: You know, it
13 somewhat is, but it's even more fundamental
14 than that. It's really sort of -- you know,
15 I'm not exactly sure how to state it without
16 actually having something that I will assume
17 some responsibilities to the degree I am able
18 to be a full participant in patient and family
19 -- person- and family-centered care.

20 So maybe it's just another concept
21 that needs to be in there, because I think
22 once that's there, then the other pieces of it

1 sort of fit with where my responsibilities
2 might be. So I don't know if that seems to
3 answer -- I felt that it was missing it, and
4 that it really was leaning more on what's
5 other people going to do to make my care
6 better, when in fact I need to come to the
7 table too.

8 We know that there are going to be
9 some limitations for some people on that. But
10 we as a team need to figure out what that is.
11 So it feels to me like it's still one more
12 statement, and I'm not sure if it -- and then
13 with that one statement, maybe there's other
14 way we can look at some of these others as
15 being redundant.

16 MS. PACE: So and then to answer
17 your question about the other suggestions we
18 heard, I think, you know, we're obviously
19 going to take those all into consideration.
20 The charge for the afternoon will not be to
21 continue working on the core concepts, but to
22 start thinking about measure concepts.

1 So I think it will be an iterative
2 process, that as you get into that, it will
3 also maybe change our thinking a little bit
4 about the core concepts. But we huddled about
5 that a little bit about the core concepts.
6 But we huddled about that a little bit.
7 Should we really, you know, as a big committee
8 continue to work on, you know, changing the
9 words, etcetera, and we think that maybe still
10 going into the exercise to work on measure
11 concepts, will also help us sharpen maybe how
12 we want to view the core concepts.

13 So we kind of see this as an
14 iterative process. So your comments are not
15 being lost. They're all being recorded, and
16 we will definitely take this all into
17 consideration, and maybe that's something that
18 we'll be able to come back to tomorrow.

19 But we want to keep moving, but
20 certainly when you're in your small groups,
21 you'll be thinking about those things, and
22 certainly we can continue to think about how

1 we want to hone those core concepts to be the
2 sharpest they can be, and as parsimonious as
3 they can be.

4 MEMBER LEFF: I just want to build
5 on Sally's comments about this notion of
6 preparedness or responsibility. I think that
7 really is a very important concept to try and
8 bake into this for a few reasons. Number one,
9 I think that if, you know, at some level
10 measures like gets developed, a measure set
11 needs to be sold in some way to users;
12 otherwise, it's dead.

13 I think that in terms of making this
14 more acceptable to the provider world,
15 providers who hear that patients actually have
16 some skin in the game, and have to actually
17 bring something to the table, I think that
18 actually helps quite a bit in moving the
19 construct forward. So just put something in
20 for that.

21 MEMBER DUBOW: I actually wanted to
22 ask Kevin a question about his observation,

1 but I have to demur here. I worry a lot about
2 the skin in the game term, which forgive me,
3 I hate, and I think we have to be very careful
4 about the patient responsibility, the way it's
5 framed. There are patients for a whole host
6 of reasons who have no capacity to be engaged,
7 and I think it's the responsibility of a
8 clinician to dance with the one you bring to
9 the dance.

10 It's just -- it's some patients are
11 easy to deal with, some are not. But saying
12 that oh, the patient was impossible is an out
13 that I just don't think should be allowed. I
14 have grave -- I know that's not what you're
15 saying, and I know and I agree that we need to
16 equip people with the information and the
17 confidence and the tools to manage their care
18 when it's feasible.

19 But I think we have to be real about
20 the fact that there are people who are going
21 to need, you know, just major effort to push,
22 you know, because there is a patient who just

1 doesn't get it, who doesn't have the capacity,
2 who has no caregiver to support.

3 I just think we have to recognize
4 that again, it's not so easy, and when we can
5 do it, great. But I think we need to be
6 careful with our language, because it becomes
7 a political weapon, and I don't think we want
8 to go in that direction. But Kevin, I wanted
9 to ask you about your observation about
10 systems.

11 Again, my very narrow focus here is
12 that if we identify the concepts, then the
13 measurement that we think about can deal with
14 issues around attribution and all of the rest.
15 So that as long as the various settings of
16 various providers are, you know, have some
17 responsibility for the outcome of that
18 particular part of the core concept, then
19 doesn't it get taken care of in the
20 measurement area?

21 MEMBER LARSEN: I think so, but I'll
22 just say from years of developing quality

1 measures, that they're currently highly tuned
2 to our fee for service system, at least the
3 ones that I'm thinking about in the federal
4 space, and that has its own set of
5 constraints, that all of the sudden quickly
6 narrow the measures into the purpose of
7 federal payment program, fee for service
8 models.

9 So insomuch as there is an
10 opportunity to measure, tightly aligned to a
11 PQRS fee for service system, great. Sometimes
12 what we find is the outcome attribute we
13 really care about is very difficult to measure
14 at one doctor, through their fee for service
15 claims model.

16 I'm just asking us to be sure that
17 we've articulated -- sometimes if it's an
18 individual behavior question, if it's a
19 microsystem question, if it's a miso or macro
20 system question, I think we're likely going to
21 be best served by some discussion across to
22 those things, so that when we're out of here,

1 we have a more sophisticated sense than this
2 is just an individual person's behavior issue,
3 or that there's the only lever we have, is
4 that a public health large-scale system.

5 I think we've got levers along the
6 spectrum, and we're going to have to be
7 thoughtful enough that our outcomes will span
8 those.

9 MEMBER DUBOW: Well, it's a question
10 of identifying the expectations and expecting
11 whichever level of the system, whether it's at
12 the individual level, a team or a larger
13 system, has to take accountability and
14 responsibility for recognizing and honoring
15 that behavior.

16 So you know, I mean I just think
17 that there is room to think about using the
18 measurement space to think about attribution,
19 and to think about levels of accountability,
20 without being saddled with messing up our core
21 concepts.

22 MEMBER LARSEN: Yeah, agreed, and I

1 just -- just to be fair, I kind of come from
2 a systems engineering standpoint. So one of
3 my favorite quick little stories, if any of
4 you have read the Virginia Mason transforming
5 health care using Lean, patient-centered model
6 using Lean, the point that they talk about
7 there is bringing some Japanese Lean experts
8 over to their health system that they're
9 really proud of, and say look at how
10 fantastic, you know, we're doing at this.

11 These Japanese Lean experts say
12 well, what are all these rooms with all these
13 chairs, and they say well those are waiting
14 rooms. They say wait happens in waiting
15 rooms? Well, they said patients wait, and the
16 Japanese said doesn't it embarrass you, that
17 you have people wait.

18 The people at Virginia Mason said
19 well of course people wait. That's what we
20 have waiting rooms for, and the Japanese
21 people said but isn't their time valuable?
22 Isn't all of this about making sure that

1 you're really efficient and tuned to them?

2 So there's not one single actor like
3 in that, and unless you open up the
4 measurement space to that sort of systems
5 level measurement, like what if a measure was
6 how much square footage you have dedicated to
7 waiting rooms, and the ultimate goal is zero,
8 you would never -- you'd never like focus the
9 right kind of work at that problem.

10 MEMBER WALLING: Well, I just had a
11 question about number four, and the use of
12 care partner. I wanted to make sure that this
13 included in a care planning for future, when
14 you may not be able to make your own
15 decisions, to preserve autonomy, even after
16 you lose your decision-making capacity.

17 So I choose the care partner. I
18 wasn't sure if that meant a family care
19 partner or a friend care partner, or a
20 provider care partner.

21 MS. PACE: Sally, do you want to
22 talk about care partners, because I know we --

1 CO-CHAIR OKUN: Yeah. I was kind of
2 surprised that we didn't get any -- a lot of
3 reaction to it frankly. But you know, in the
4 interests when we were having one of our chair
5 meetings, and we were struggling over the
6 providers and clinicians and the words and
7 then family, and so finally it's becoming more
8 and more used in circles that I've been at
9 lately, with this concept of where it's a
10 partnership.

11 So I said well, maybe we should just
12 be calling ourselves care partners, you know,
13 and yet that's a new term, it's a new way of
14 thinking and I'm not sure, you know. If we're
15 going to use things like that, we need to
16 define them, and we need to be more clear
17 about them.

18 So I was actually waiting for some
19 reaction and didn't get some. So I guess it's
20 time for us to decide that sort of thing. So
21 I think in this statement it was meant that
22 whom I choose will be the one who's making my

1 decisions. That presumes that I may have done
2 some advance thinking about who that might be,
3 if I can't do it for myself. But that gets
4 back to the preparedness question.

5 So my influence is on that
6 particular statement. I didn't explain that
7 influence by saying well that presumes that
8 someone's actually made some active step to
9 name someone.

10 In the absence of that, however, I
11 would also suggest that as teams, and if we're
12 well-functioning teams, that we also have also
13 identified who amongst us on the team might be
14 the best to take the responsibility to sort
15 out how can we best be sure that decisions get
16 made, in the way that we believe this person's
17 decision-making would drive, if they could do
18 it themselves.

19 So it doesn't necessarily need to be
20 a family member. It could be if I'm able to
21 designate that person, and I'm prepared enough
22 to think about putting that in place ahead of

1 time, great. If I haven't, to the degree I'm
2 able, I'm asked about that, and when I'm not
3 able, somehow or another this person and
4 family-centered environment considers that my
5 incapacity leaves me unable to make that
6 decision, and defines within the team how best
7 to do that, either through the structure of
8 the organization I happen to be in, by virtue
9 of where I'm getting my care and how that gets
10 determined that way.

11 So I think there's a bit of openness
12 left in here, and some interpretation needing
13 to be thought through, in terms of where the
14 measures might fall out. But the intentional
15 of care partners was an inclusive term, family
16 as well as other people who matter to us, as
17 well as the people who are providing our
18 clinical care.

19 MEMBER MACDONALD: Having not been
20 involved in the original draft of this, what
21 was the reason for not saying family, and then
22 defining family as CMS does, where patients

1 have a right to choose whoever they want to be
2 their quote-unquote family?

3 MS. PACE: Actually, it does say
4 this in the definition, their defined family.
5 So basically, the idea is that the patient
6 defines who their family is, and then --

7 MEMBER MACDONALD: And so with that
8 in mind, why wouldn't we use the same
9 terminology throughout the documents? I think
10 this is going to be very confusing, having one
11 regulatory agency use family and defines it as
12 it is defined earlier on. I guess I was
13 speaking to the definition you're using under
14 core concepts confusing.

15 MS. PACE: So your suggestion is
16 that we should use family, and what term would
17 you like to use for everyone else? Do you
18 like care partners?

19 MEMBER MACDONALD: Well, the patient
20 defines who family is.

21 MS. PACE: Exactly.

22 MEMBER MACDONALD: So I would just

1 put that in there. I mean I'm simplify it.

2 MS. PACE: But how would you -- you
3 don't, you're not going to consider clinicians
4 part of the family?

5 MEMBER MACDONALD: No, no.

6 MS. PACE: So then the question is
7 what term do you want to use for --

8 (Off mic comment.)

9 MEMBER RADWIN: In all the anecdotes
10 we heard, what role is not included in
11 clinician?

12 CO-CHAIR OKUN: I would suggest as
13 most of us think about the word "clinician,"
14 we wouldn't necessarily think about the health
15 coach that Gene had described. That would be
16 my impression. It wouldn't necessarily be my
17 opinion, but I think that that person might
18 not be someone seen as a clinician.

19 MEMBER RADWIN: How about "clinical
20 team" then?

21 (Off mic comment.)

22 MEMBER LATTS: Is somebody not using

1 their microphone?

2 MS. PACE: Sorry about that. I was
3 saying that part of the thinking of using care
4 partners was to really emphasize what we say
5 in the definition about collaborative
6 partnerships. So but certainly, you know, I
7 think the point about family is well-taken.
8 We can just refer to family in the appropriate
9 places.

10 But again, we can say providers.
11 The other term that we had been using was
12 providers of care, which could encompass
13 clinicians and everyone else involved.

14 MEMBER deBRONKART: So I'll
15 acknowledge that I've just walked in on this,
16 so I hope I'm not redundant. It seems to me
17 that the context for the whole relationship is
18 essential, and is actually more important or
19 at least as important as how we identify
20 people within that context.

21 What I see and hear about so often
22 is -- and I know many people have said this,

1 but I think it's our job to hammer on it, the
2 absence of a team culture and team-oriented
3 behaviors, just the fact that you can have six
4 different people, six different doctors, and
5 I know the culture is I'm in my silo and I
6 don't care about you.

7 Nobody would say that, but it's the
8 reality, and so if we have the team culture,
9 then you have people who basically work at the
10 practice, right, and you have the family, the
11 patient, the family, the caregivers, everybody
12 who doesn't work at the practice, who comes to
13 the practice for care, right.

14 And sure, we may need to come up
15 with a term for the people who work at the
16 practice, but I think the more important thing
17 is the sense of a functioning team.

18 MS. PACE: Okay.

19 CO-CHAIR OKUN: Can I just add an
20 anecdote to this, and that is part of this I
21 will have to admit is influenced somewhat by
22 another project that I've been involved in for

1 some time now, and a few years ago, as part of
2 the IOM workshop work group on team-based
3 care, we created a document called core values
4 and principles of team-based care.

5 One of the things that we worked on
6 a lot was thinking about what are the roles
7 and responsibilities. What are the core
8 values that team members need to have, and one
9 of the things we realized late into the game
10 was that we really were talking solely about
11 the professional or the clinical team members,
12 and we actually left out what roles and
13 responsibilities might family and patients
14 have in this situation?

15 So actually a follow-on project from
16 that, particularly that first paper, was now
17 we are -- have convened a work group. We've
18 been working now for just about a year on the
19 patient's role as a member of the team, and
20 thinking about what does it mean to be a
21 member of the team.

22 For those people who may not want to

1 be a member of the team, we need to
2 acknowledge that and understand that. But
3 that by not suggesting that they're a member
4 of the team sort of marginalizes them
5 somewhere along the way. Again, puts them in
6 the center, but isn't necessarily saying I'm
7 in this with you.

8 So some of that's been influenced by
9 that, and I think the definition where we
10 state collaborative partnerships among
11 individuals, defined family and providers of
12 care was really where sort of this notion of
13 care partners emerged from.

14 So that said, I just want to give a
15 little context, because we are actually in
16 conversations on a few different levels in a
17 few different groups, and it's getting
18 influenced and leakage starting to spill over
19 to different ones.

20 MEMBER deBRONKART: Well and coming
21 from an engineering background, and I also --
22 I mean as a student, I'm both a student and a

1 victim of disruptive innovation.

2 My industry typesetting machines got
3 disrupted all to hell by desktop publishing,
4 and what I saw was you could look at an
5 overall process map, except I mean in vague
6 terms, not micro-details, of what happens over
7 the course of time that was useful, that
8 produced some value.

9 What we're seeing, and this goes
10 directly to why Sally's point is so important,
11 is that there is a shift in where certain
12 activities get done, all right.

13 Now in the context of diabetes, I'm
14 told that 100 -- I'm not expert on the
15 disease. I'm told that 100 years ago, in
16 order to know what your numbers were, you had
17 to go to a doctor, right, and clearly knowing
18 what your numbers are is useful. That no
19 longer requires going to a doctor, and we
20 won't understand how things are shifting and
21 how we need to reach out on things, if we
22 don't realize that.

1 So and because what's happening,
2 like in Kevin's story, a whole bunch of things
3 are actually done effectively in the home,
4 which takes a load off the system, which in
5 turn of course points to the other, the mega-
6 elephant in the room, which is that there are
7 a whole lot of people who don't want their
8 income to drop, as more work gets done
9 outside.

10 MS. PACE: Bruce.

11 MEMBER LEFF: So just a comment.
12 We've been talking about "the team." I think
13 one of the implications, or at least an
14 inference that I've drawn is that I think much
15 of the conversation is in a primary care
16 context. Maybe not completely, but I think
17 that's a reasonable inference to draw, and I
18 think we've been talking about team as a
19 monolithic thing, one patient, one team.

20 I'm reminded of some very excellent
21 work that Hoangmai Pham published a few years
22 back in Annals of Internal Medicine, which

1 suggests that the average older -- average
2 Medicare patient with multiple chronic
3 conditions sees on average three different
4 primary care physicians, which really screws
5 things up at some level.

6 The other thing I would just throw
7 out there is that -- and I do a lot of care in
8 the realm of home-based primary care, where
9 seasoned folks with multiple chronic
10 conditions, functional impairment, cannot
11 access the usual ambulatory care system. Lots
12 of social overlay onto their medical
13 conditions.

14 In truth, you really cannot manage
15 that population effectively without probably
16 somewhere in the neighborhood of 10 to 15
17 different types of services that need to
18 impact on that patient, that go way beyond the
19 medical, way beyond the medical.

20 So if you're actually thinking about
21 person-centeredness to affect a set of
22 outcomes for people who really need the most

1 person-centered care, I think you have to
2 think very broadly in terms of scope, of what
3 that team looks like. But again, that creates
4 various levels of complications, attribution,
5 etcetera, etcetera.

6 MS. PRINS: Chris.

7 MEMBER FORREST: I think the core
8 concepts are very reasonable, and they will be
9 -- they lend themselves to creating
10 operational measures, which is a very nice
11 piece of this.

12 But they're possibly incomplete, if
13 we really want to take into account the fact
14 that patient- and family-centered care,
15 person- and family centered care is not only
16 an experience of a person, but it's also a
17 system level attribute.

18 So when you say "my care partners
19 value," that is an experience of person- and
20 family-centered care. It is not the system
21 attributes that enable providers within that
22 system to affect that outcome. So we could

1 think about this as a driver diagram, where
2 the outcome is the experience of person and
3 family-centered care.

4 It does matter if the patient or the
5 individual experiences that. Then there are
6 these eight primary drivers. These are things
7 that have to happen on the ground, very close
8 to the patient. But then the secondary
9 drivers are the system-level attributes, the
10 things that you can actually change from a
11 policy perspective, that influence the primary
12 drivers.

13 So that's missing from the core
14 concepts. On the conceptual level, they're
15 there, but the way these are written, they're
16 only focused on the primary drivers. So I
17 think we're missing a big opportunity for
18 measurement.

19 MS. PACE: And that's what we'll get
20 into with the measurement framework, exactly.
21 So we'll --

22 MEMBER FORREST: But it also gets to

1 the wording. I mean yeah, the measurement
2 framework's important, but it's how these are
3 worded, and some recognition perhaps in the
4 preamble that we recognize that this is the
5 experiences of, but that there are system-
6 level attributes that influence the capacity
7 to achieve these.

8 MS. PACE: Okay, good.

9 MEMBER MACDONALD: I think that's
10 what I meant by structural actually. I mean
11 it's what's behind this outcome, and I think
12 that is a very important point.

13 I just wanted to weigh in quickly on
14 the care partners, that I do find it rather
15 confusing. From a lay perspective, it's not
16 a term that I'm familiar with, and if it means
17 both clinicians and family, then I think it
18 can be quite confusing.

19 Like in four, "I choose the care
20 partner I prefer to collaborate in those
21 decisions for me." I don't know if that's the
22 family or the clinician. So it just would be

1 good to separate it in some way.

2 MEMBER EAMES HUFF: I also am going
3 to comment on the my care partners. I do like
4 that it's broad to get sort of all-
5 encompassing, but I would agree that having
6 family in there is too broad and a separate
7 concept. The thing that I think is missing
8 from it is it seems very clinician-focused,
9 and I think there are some other people
10 involved in care that actually help with
11 patients under care.

12 So I'm thinking of like
13 receptionists, administrative staff, you know.
14 It could be the person that is the cafeteria,
15 things like that. Those touch points are
16 really important and getting on them. I don't
17 know if -- I don't think we're planning on
18 doing measurement in all those areas, but I
19 think sort of recognizing that there's non-
20 clinical staff that are really important.

21 MEMBER JHINGRAN: So two comments.
22 What I've been thinking about is how can you

1 make the same core concepts for a very
2 simplistic patient versus the more complicated
3 patient, and an analogy which came to my mind
4 is I'm sure everybody's familiar with the SF-
5 36, which is a health status questionnaire.

6 You have a six-item version and then
7 you have a 36-item version. So you could
8 still have the same core concepts, but go
9 deeper and more granular for the more
10 complicated patients. So that's a thought
11 that came to mind.

12 The other thought is, and again this
13 could be going into measurement, but you could
14 have the same core concept, but it's going to
15 look different from the perspective of the
16 patient versus the perspective of the
17 clinician.

18 So you could have the clinician
19 portion or a health care partner portion, and
20 the patient portion, and then you can get even
21 more sophisticated by looking at concordance
22 between the two. Because the patient might

1 say my physician did not communicate, whereas
2 the physician might say I did.

3 So understanding what that
4 concordance is, and understanding where the
5 true gaps are and where the strengths are,
6 where things are going well, could be ways to
7 kind of get to issues which finally make a
8 difference in the patient's care.

9 MS. PACE: Ellen.

10 MEMBER MAKAR: So regarding the care
11 partners, I was thinking if you wanted to just
12 say family care partners and then the other
13 care partners, that might work, and then I
14 agree. When we were talking about non-
15 clinical folks, I think they need to be
16 included.

17 But also I think administration, and
18 that's more of a structural or a secondary
19 driver, is including that level for acute
20 care, but also across the span and in a way
21 trying to put in the payors, because we are
22 kind of missing that piece, and we know that

1 a lot of that decision-making is driven that
2 way. So just a way to think about that.

3 Lastly, we were also talking about
4 what you were saying. So I think it might be
5 a helpful exercise to look at these the other
6 way, because these are very much the patient
7 speaking, and it would be interesting for the
8 care partner to say what would be person- and
9 family-centered care. How would they deliver
10 that?

11 CO-CHAIR OKUN: I was going to add
12 one comment on that. The intention of the
13 word "care partners" at the time that we
14 played around with this was frankly to be
15 inclusive of whomever's touching the patient.

16 So I know that that's way broad, but
17 it was one attempt to be able to say, you
18 know, one patient-one team concept, as Bruce
19 mentioned, actually came up in an IOM meeting
20 a couple of weeks ago from a patient, who said
21 I just -- I'm one patient. I want one team.

22 I understand that that team may be

1 lots of you and you may not be connected, and
2 you may be in different places, but you figure
3 that out, and help my care seem like it's
4 coming from one team.

5 So the idea of the care partners was
6 really sort of that inclusive idea, that it
7 could be -- it could someone in their book
8 club who supports them on some level
9 emotionally, and it's the only person they're
10 able to talk to about where their anxieties
11 are and stuff.

12 MEMBER NELSON: I fundamentally -- I
13 think the idea of moving towards the term
14 person not patient is a good idea, focusing on
15 partners, not providers vis-a-vis caregivers
16 or other supports is a good idea. It's a
17 direction that we'd like to move to.

18 I'd like a friend who had a rare
19 form of cancer in our neighborhood. He
20 actually didn't come to our system. He went
21 to Fred Hutchinson. He came back and he was
22 bragging about the care team he had at the

1 Fred Hutchinson Cancer Center in Seattle, that
2 he had a great team and he was the captain, in
3 a very rare form of cancer.

4 Then he came back and has a primary
5 care system and a cancer support system. So
6 he's still alive and doing very well. But I
7 think this idea of care team and me in the
8 center goes from primary care to cancer care
9 to well child care etcetera, and it's the
10 correct direction to move towards.

11 It's an intriguing idea, to build on
12 Chris' point and others have made the point,
13 that it would be good to have a summative
14 statement/future measure of overall person-
15 centeredness, not patient-centered but person-
16 centeredness, and in the -- in the IOM Chasm
17 Committee discussions, now at least a decade
18 ago, the overall sentiment around person-
19 centered care was a paradox and controversial.

20 But I get everything I want and need
21 exactly when I want and need it, and the
22 paradox is what I want and what I need may be

1 two different things. But we live with
2 paradoxes. But I think it would be helpful if
3 we could have an over-arching sentiment, that
4 could relate to the overall macro system, you
5 know, the whole system and not pin it on a
6 particular Troy, my doctor Troy or my doctor
7 Jeff or my doctor Annie, that it's really as
8 we move into person and population health, we
9 want to move our attribution out to the system
10 that's providing personal and population
11 health.

12 MS. PACE: Okay, Ann. One last
13 comment and then we'll move onto the next
14 session.

15 MEMBER WALLING: It's really brief.
16 I just -- when I was reviewing the materials
17 before the meeting, I found it actually very
18 clear to read the summary of the principles
19 that was on the agenda. So at the 10:30 a.m.,
20 when it just listed 1-2-3-4-5 --

21 MS. PACE: The short ones?

22 MEMBER WALLING: Yeah, the short was

1 easy for me to comprehend and kind of -- it's
2 just a thought.

3 Measurement Framework

4 MS. PACE: Okay, all right. Well,
5 we're going to switch gears a little bit. I'm
6 going to do a brief overview, talking about
7 the measurement framework, and this was in
8 your materials and it's also in some
9 information in your packet, and we'll stop at
10 2:20, because we have some people joining us
11 by webinar, and then we can resume just prior
12 to going into our breakout groups.

13 So next slide. So I'm going to
14 again put this a little bit into context just
15 so that you have these things in the back of
16 your mind. But NQF does endorse performance
17 measures that are based on an evaluation of
18 the measure against a standard set of
19 criteria, to ensure it is suitable for
20 accountability applications, in addition to
21 performance improvement.

22 So the measures that NQF endorses

1 are intended to be -- obviously, we want
2 measures that will be useful for improvement,
3 or to identify where we need to improve. But
4 they're also intended to be used in public
5 reporting, pay for performance, etcetera.

6 Next slide. So these are our basic,
7 our major criteria. The first one includes
8 evidence, performance gap and priority, and we
9 refer to this as importance to measure and
10 report. This is a must-pass criterion, and
11 I'll talk a little bit more about that,
12 because it's most relevant for measure
13 concepts.

14 But I just want to -- the reason we
15 put this first is if it's not really important
16 to measure and report, then we really don't
17 need to worry about whether it's reliable and
18 valid. What would it be measuring? The next
19 criterion is reliability and validity, which
20 we refer to as scientific acceptability of the
21 measure properties.

22 This is also a must-pass criterion,

1 and again, if it's not reliable and valid,
2 then we have risk and misclassification and
3 improper interpretation. Again, think of this
4 in the context of being used not only for
5 improvement, but for accountability.

6 Feasibility, because we want
7 performance measurement to create as little
8 burden as possible. However, that's not a
9 deal-breaker and hopefully, you know, we can
10 improve on feasibility over time if it's
11 something really important to measure.

12 Usability and use, that we really do
13 want to see a plan for the measure to be used
14 in an accountability application. If it's
15 not, then you know, NQF endorsement may not be
16 necessary. Then we have a process of looking
17 at related and competing measures, to try to
18 minimize burden.

19 So just a little bit more about the
20 importance to measure and report, and this
21 will play out as we go through these slides.
22 But our criterion is about the empirical

1 evidence for a structure, process or an
2 intermediate clinical outcome, and we have
3 very specific guidelines about the quantity,
4 quality and consistency of evidence, to
5 support having a national standard performance
6 measure on a structured process or
7 intermediate clinical outcome.

8 With outcomes, we really want to see
9 a rationale that outcome is influenced by at
10 least one health care structure process,
11 intervention or service. Remember that we
12 consider PROs and experience with care as
13 outcomes.

14 So we're not asking for systematic
15 reviews of evidence of what influences an
16 experience with care outcome. If it's
17 important to patients and consumers then, you
18 know, it's an important experience, as long as
19 there is something that the health care system
20 can do to influence that.

21 Performance gap, and this includes
22 disparities across population subgroups. But

1 we really, if we're going to invest in a
2 national performance measure that requires
3 data collection and reporting, we really want
4 it on something that is not already a terribly
5 high level of performance, because if
6 everyone's doing it, then we probably don't
7 need to invest in a whole system to be
8 collecting and reporting on it.

9 High priority, and this I mentioned
10 earlier for PROs. We really do want to see
11 some information demonstrating that it's
12 valued and meaningful to patients and
13 consumers, and then there's a criterion about
14 composite performance measures that we won't
15 get into any detail today.

16 So just again, some clarification.
17 Some of you did participate in the PRO and
18 performance measure project that we had in
19 2012. But one of the things that we learned
20 as we were going through that and talking to
21 one another, is that we did need to clarify
22 our language.

1 So I just wanted to mention this,
2 you know. We really considered PRO, the
3 patient-reported outcome, which you saw a
4 definition earlier, as kind of the concept,
5 and we have two examples here, one of
6 depression and one with a person with
7 intellectual or developmental disabilities.

8 The PROM is the instrument or a
9 single item measure. So you know, the PHQ-9,
10 in the case of the intellectual developmental
11 disability, the single item measure might be
12 do you have a job in the community.

13 Then the PRO-PM or the PRO-based
14 performance is what -- when you actually have
15 that patient-level data, and aggregate it out
16 to be able to say, for example, what
17 percentage of my patients with a diagnosis of
18 depression actually had remission of their
19 depression symptoms within six months or 12
20 months, or in the other case, the proportion
21 of people with intellectual or developmental
22 disabilities who have a job in the community.

1 So again, just to kind of get our
2 minds around, because I think a lot of the
3 things that we'll be talking about with
4 person- and family-centered care might be
5 experience measures and to think about the
6 patient level measure versus a performance
7 measure, where you aggregate that information.

8 So I also wanted to just talk a
9 little bit more. Uma mentioned it this
10 morning about the PRO-PMs and relation to
11 person- and family-centered care. Certainly,
12 a lot of the core concepts, and I think
13 several of you mentioned this, really seem to
14 be in the PRO domain of experience with care.

15 It is describing what the patient or
16 family should experience, if they're, you
17 know, receiving person- and family-centered
18 care, or participating in person- and family-
19 centered care.

20 So and that would be a patient-
21 reported outcome, generally collected in a
22 survey. We're familiar with CAHPS surveys,

1 for example. PRO-PMs for other domains, such
2 as health-related, quality of life, functional
3 status, symptom and symptom burden, health-
4 related behaviors are very important, but they
5 may be more indicative or indicators for
6 quality of care in the other domains. So
7 effectiveness of care, safety, etcetera.

8 So this is where it gets a little
9 dicey, because using a patient-reported
10 outcome may be very important in delivering
11 person-centered care, but aggregating the data
12 for that outcome.

13 So for example, if you measure
14 function and patients who are having a hip
15 replacement surgery, and you want to have a
16 performance measure of the percentage of
17 patients with improved function after hip
18 surgery, that may be very important for the
19 patient.

20 So having discussed that with the
21 patient and measuring that with the patient,
22 an important part of person-centered care.

1 But if you're looking at the percentage of
2 patients who had improved hip function, that
3 may be more of an indicator of the clinical
4 effectiveness. So again, we'll have to kind
5 of sort through these things, but just kind of
6 laying these things out for you to have in the
7 back of your mind as we start into our
8 exercise to look at measure concepts.

9 The other thing to keep in mind
10 about using PRO measures or PROMs in practice,
11 is that they may not even be indicative of
12 providing person-centered care, if they really
13 are just a data collection vehicle.

14 So you know, sending out a PRO
15 instrument to a patient, but never discussing
16 the results or using it in, you know, planning
17 the care, monitoring progress would probably
18 not be very person-centered. It's really a
19 data collection process.

20 So again, there's all these
21 potential interactions and things. You know,
22 just because it's a PRO doesn't mean it's

1 measuring person-centered care, and it doesn't
2 mean that using it if it's just a data
3 collection vehicle.

4 Okay, next slide. Okay. That's all
5 right. Some other things to keep in mind when
6 you're thinking about measure concepts is that
7 again, you know, meaningful to consumers and
8 built with consumers, focused on the entire
9 experience rather than a single setting or
10 program to the extent possible, and measured
11 from the person's perspective and experience,
12 when that's the best source of information.

13 Certainly when you're talking about
14 a patient's experience, they're going to be
15 the authoritative source.

16 Next slide. So just wanted to talk
17 a little bit about, you know, I'm sure you're
18 all familiar with the kind of classical
19 structure process outcome assessment of
20 quality, and in general, NQF has a
21 hierarchical preference for measures of
22 outcomes, and then intermediate outcomes and

1 finally process and structures that are most
2 closely linked to desired outcomes.

3 So again, as you're thinking about
4 performance measures or measure concepts for
5 performance measurement, to be thinking about
6 this, in terms of what is the evidence that a
7 structure or process is really going to affect
8 that outcome or experience of patient-centered
9 care.

10 The other thing that happens, and I
11 know someone already mentioned about sometimes
12 performance measures or processes end up being
13 kind of a checkbox, and this is just to talk
14 about that, you know again, if we're going to
15 measure a process, we want something that's
16 closely linked to the desired outcome.

17 So this just kind of illustrates
18 that you may have, for example, that you're
19 going to use patient-reported outcome
20 instruments in delivering care, and you may
21 have a structural -- the structure is that
22 your organization has a policy and procedure

1 to use these patient-reported data. They've
2 identified a set of PROM standard data
3 collection instruments that have been
4 validated.

5 Then in the process realm, staff
6 have to identify which PROM to use with the
7 patient, ask the patient to complete the PROM,
8 review -- actually review those results with
9 the patient, and then use as a basis for
10 planning care, monitoring progress.

11 So my point here is is that if we
12 have a performance measure that says, you
13 know, you use PROMs, it kind of gets in that
14 realm of what people criticize, is that you
15 know, you're just checking a box, and just by
16 using the PROM, it's not going to ensure that
17 you reach the outcome. You have to do all
18 these other steps.

19 So it's kind of one of those things
20 that it's necessary but maybe not sufficient.
21 So you know, just measuring something that's
22 very distal and that requires multiple steps

1 before you actually achieve the outcome, may
2 not be the most efficient place to put our
3 resources for performance measurement.

4 Next slide. Okay. So if we're
5 looking at the, you know, outcome, process and
6 structure, again you know, right now the way
7 the core concepts are worded and as several of
8 you mentioned, these seem to be kind of in the
9 realm of the patient's experience, what they
10 will experience. So we would see that as an
11 experience with care outcome.

12 There could be various processes
13 that will help support reaching that
14 particular outcome, and these would be the
15 interactions between the health care system
16 and the person and family, including
17 interventions, treatments and services, and
18 then there can be structural measures or
19 organizational structures and system that
20 support providing person- and family-centered
21 care, and we already talked about some of
22 those.

1 So this leads me to what we started
2 in the draft about a measurement framework if
3 we were using the structure process outcome
4 aspect, and if you all have a copy of that in
5 your folders here, and this is just the very
6 first one.

7 This is just for illustration. This
8 is not to suggest this is what we should be
9 measuring. It's just to get you thinking when
10 you get into our next exercise, in terms of
11 starting to think about measure concepts.

12 We would probably encourage you to
13 think about measuring the outcome directly or
14 the experience directly, or other things that
15 might be considered outcomes, and then you
16 know, are there processes and structures. I
17 think it's important to --

18 I think several of you already have
19 mentioned that in this area, there are
20 probably lots of different processes and
21 structures that will support achieving those
22 core concepts, and they may vary according to

1 the patient context or service context or
2 setting context.

3 So it may be very challenging to try
4 to identify processes that rise to the level
5 of, you know, this should be a national
6 standard performance measure, meaning pretty
7 much everyone should do it, and do it in a
8 prescribed way.

9 So again, just to be thinking about
10 when you start looking at potential measure
11 concepts, some of, you know, how these things
12 might be structured that support our
13 processes, and where do we really want to
14 focus performance measurement, especially from
15 the standpoint that many of you had brought up
16 about parsimony and simple.

17 I think that will be our challenging
18 going into these groups, of how can we achieve
19 this as simply as possible.

20 So as you start thinking about it,
21 there's several again questions to keep in
22 mind. Is there evidence for structures or

1 processes that would indicate all specified
2 entities should really implement in their
3 systems of care and be the focused of an
4 endorsed performance measure?

5 The next question, and I'll take a
6 few minutes, is could information on some
7 structures or processes be useful in a
8 standard label, and I'll give you an
9 illustration of that. Are there outcomes that
10 could be measured besides the experiences
11 represented in the core concepts?

12 And again, you know, where patient-
13 reported outcome measures fall in measuring
14 person- and family-centered care. So next
15 slide, and then we'll go on to our next
16 speakers.

17 So Kevin brought this idea up early
18 on in some of our discussions, is could there
19 be a nutrition label for person- and family-
20 centered care? So I think kind of the essence
21 of the nutrition label idea is you have a
22 standard set of items. There's standard

1 definitions that go with these. There are
2 standard ways to present the information, and
3 generally a standard format or layout.

4 So next slide. This is just, you
5 know, the question. Are there certain things
6 that would be useful to lay out in a standard
7 way, that would be useful to patients and
8 consumers, that would indicative of person-
9 and family-centered care?

10 You know, I put some in here just to
11 stimulate thinking, but you know, and these
12 may or may not be the right ones or useful
13 ones or maybe nothing. But it is something
14 for us to think about as we go into our small
15 groups, and of course the key thing is, you
16 know, would it be useful to patients and
17 consumers.

18 But a couple of things on here. For
19 example, you know, communication options. Can
20 people communicate by phone, email, text
21 messaging? Do they have access to their
22 medical record? Is there a connection between

1 personal health record and their medical
2 record? You know, are there patient and
3 family support groups?

4 Maybe the first one is just do they
5 have a patient and family advisory group? You
6 know, so maybe think about, you know again,
7 we've all had experiences as patients and
8 patient advocates, to kind of think about, you
9 know, if you had information at a glance, what
10 would be useful?

11 These may not -- and also these may
12 be things that aren't, don't lend themselves
13 well to a typical performance measure. But
14 you know, you can have things on here like a
15 link to their quality performance measures or,
16 you know, people have been talking about
17 affordability and transparency of cost, a link
18 to a price list.

19 So just think about, you know, what
20 might be useful in terms of, you know, gauging
21 person-centeredness or at least finding a
22 provider that matches your preferences. Yes,

1 go ahead.

2 MEMBER LARSEN: So the reason to
3 bring this up, that part of my research life
4 is in health literacy, and health literacy, I
5 kind of started thinking about reading, that
6 really evolved as a science around how do
7 consumers of health care understand
8 information and make decisions.

9 One of the things we studied in the
10 health literacy world was the nutrition label,
11 and the reason for that study was because they
12 made some fundamental shifts in the labeling
13 world, and those shifts didn't actually change
14 the measurement exactly. They standardized
15 information display, to help with better
16 comparability.

17 So an example is serving size. So
18 it used to be that the companies that produced
19 food could decide whatever serving size they
20 want, and then they would tell you how many
21 calories and how much fat and whatever else
22 was in it. What they did with nutrition, the

1 new nutrition label was say we're always going
2 to define serving size for liquids as eight
3 ounces.

4 We're always going to decide serving
5 size for carbohydrates as half a cup, and then
6 you'll get calories in a sort of standardized
7 fashion, against these sort of standardized
8 serving sizes.

9 They also called out how to
10 highlight -- to highlight particular
11 information that people thought was sort of
12 most relevant, and it seems to me as I was
13 thinking about this work about person- and
14 family-centered measurement, that part of our
15 charge to making measures that matter and that
16 mean something to consumers is not just in the
17 content, but in the sort of form and format
18 that we would recommend.

19 So this is to sort of call that out
20 and say, you know, we have an opportunity here
21 not just to talk about 15 or 30 individualized
22 items. But is there sort of a system of

1 measurement and engagement that actually gets
2 to good meaning and decision-making on behalf
3 of the people that we are hoping to work with?

4 MS. PACE: All right. So I think
5 we're going to go ahead and move on to our
6 speakers that are going to talk to us via
7 webinar. So if we could bring up their
8 slides, and let me just do a check. Is Dr.
9 Holly online?

10 (No response.)

11 MS. PACE: So I believe he is.
12 Operator, do we have James Holly, Larry Holly?

13 OPERATOR: He had just disconnected.

14 MS. PACE: Pardon me?

15 OPERATOR: He had just disconnected.
16 He's dialing again.

17 MS. PACE: Okay, and what about
18 Susan Yount?

19 DR. YOUNT: Yes, we're here.

20 Innovative Approaches

21 MS. PACE: Okay, Susan and Amy,
22 okay. So we'll wait just a moment for Dr.

1 Holly to come back online. What I -- and just
2 to again, as I said, we just asked for these
3 presenters to give us some -- they have some
4 innovative things to share with us, and again,
5 it's just to stimulate thinking. It's not to
6 say that we need to do this or but just again,
7 in the spirit of our exploring these topics,
8 and some of the things that might be possible.
9 So is Dr. Holly on?

10 DR. HOLLY: Hi, I'm here. I was
11 connecting and I hung up.

12 MS. PACE: Okay. I've done that
13 myself. So Dr. Holly is with Southeast Texas
14 Medical Associates, and he's going to talk
15 with us about his approach to person-centered
16 care, and specifically on a concept of
17 convenience. So Dr. Holly, you'll just need
18 to signal to us when you want us to advance
19 the slide.

20 DR. HOLLY: Okay. You can advance
21 it. Our practice is a multi-specialty group
22 in southeast Texas. We are accredited by NCQA

1 as a Tier 3 medical home, by Triple HC for our
2 medical home and ambulatory care, by URAC and
3 by Joint Commission. We have all four
4 accreditations.

5 We are heavily involved in patient-
6 centered care. We use CAHPS, HCAHPS and also
7 Community Council, for making sure that we are
8 focused on issues such as shared decision-
9 making, activation, engagement and other
10 subjective but critical issues related to
11 medical home and patient-centered care.

12 The concept of convenience as a
13 subsuite or placeholder for quality developed
14 a few years ago. The key to all of what we do
15 related is coordination. The statement on
16 space seems a little bit for us a
17 simplification. How can doing things the way
18 patients want, when they want, where they want
19 and how they want contribute to the
20 achievement of quality outcomes?

21 Next slide, please. This was --
22 next slide please. Oh, did I move that. Can

1 you do the next slide please? Am I not
2 connected?

3 MS. PACE: You are, you are. Just
4 let's go the next -- one slide. There you go.

5 DR. HOLLY: Okay, one slide. That's
6 it. Coordination of care is the process an
7 organization goes through to assure the
8 patient receives the care they need, and
9 coordinated care is the outcome, the
10 experience and perception the patient has when
11 the care has been organized for continuity,
12 convenience and for compliance, and use that
13 as an alliterative placeholder for adherence.

14 Next slide, please. Initially, the
15 idea of convenience and the scheduling of
16 multiple appointments at the same time was the
17 extent of our understanding of the concept of
18 coordination. Eventually, convenience was
19 translated into the understanding that
20 coordinated care means more than just making
21 patients comfortable.

22 It meant and it resulted in next

1 slide. The convenience for the patient, which
2 resulted in increased patient satisfaction,
3 which contributes to the patient having
4 confidence that the health care provider cares
5 for the patient personally, which increases
6 the trust the patient has in the provider, all
7 of which next --

8 Increases compliance, adherence and
9 the patient obtaining health services
10 recommended, which promotes cost savings in
11 travel, time and extensive care, which results
12 in increased safety, quality of care and cost
13 savings for the patient.

14 Next. This requires intentional
15 efforts to identify opportunities to schedule
16 visits with multiple providers on the same
17 day, based on auditing the schedule for the
18 next 30 to 60 days, to see when a patient's
19 scheduled multiple providers, and then
20 determine if it is medically feasible to
21 coordinate those visits on the same day.

22 Next. To schedule multiple

1 procedures based on auditing of referrals, and
2 are based on auditing the schedule for the
3 next 30 to 60 days, to see when a patient is
4 scheduled for multiple providers or tests, and
5 then determine if it's feasible to coordinate
6 those visits.

7 Next. In scheduling procedures or
8 other tests spontaneously on the same day when
9 the patient is seen and a need is discovered,
10 and fourthly, recognizing when patients will
11 benefit from case management or disease
12 management or other ancillary services and
13 working to provide the resources for those
14 needs.

15 Next. This is a care coordination
16 referral template, where a provider can, with
17 a click of a single button, two buttons, can
18 send to the care coordination department a
19 request for services, including a referral to
20 -- the SETMA Foundation, where services that
21 the patient needs but can't afford, whether
22 it's they can't afford a co-pay or has no

1 insurance that covers those benefits, that we
2 can subsidize, underwrite or pay for those
3 services.

4 Next slide. Convenience and
5 quality. It's only through this analysis we
6 accept that convenience is a worthy goal of
7 quality care, as opposed to it only being a
8 means of humoring patients.

9 This fulfills SETMA's goal of
10 seeking to be comfortable, providing adequate
11 health care to our patients, and to our
12 functionally becoming the consultant, the
13 collaborator, the colleague to our patients,
14 empowering them to achieve the health they are
15 determined to have.

16 Next. As we learned the complexity
17 of quality metrics, their focus and their
18 content will change.

19 Next. Quoting from the Institute
20 for Health Care Improvements High Impact
21 Leadership study, we learned that as we move
22 from volume to value, we are really going to

1 change some of the subjective measures, our
2 patient-centered measures.

3 For instance, with volume, we
4 focused on patient satisfaction. With value,
5 we're going to look at persons as partners in
6 their care. We're going to look at with
7 volume increased top line revenue. With
8 value, we're continuously decreasing the per
9 unit cost and so on.

10 This brings us to the whole issue of
11 trying to determine these patient-centered
12 metrics. CAHPS and HCAHPS both deal with
13 those. We deal with those in our community
14 council, when we allow patients to come in,
15 where they have a majority vote, where they
16 can impose us requirements that they see as
17 being important matters.

18 If they don't violate the Medical
19 Practice Act, federal or state statutes, we
20 will bind ourselves to that referral. In
21 regards to this process of looking at risk-
22 adjusted quality of metrics, we really rather

1 think in terms of data analytics, looking for
2 leverage points to improve the quality of care
3 for everyone, rather than trying to adjust the
4 cost of care for -- or the quality of care for
5 those who have major impediments or major
6 barriers to care.

7 We've tried to eliminate all those
8 barriers by first identifying them, and then
9 finding ways whether it's financial or whether
10 it's access to care, whether it's the
11 illiteracy or whether it's family resistance
12 or whatever the needs are.

13 It's very important, we believe, to
14 discover what those are, to be able to measure
15 them and then be able to quantify our meeting
16 of those, so that we can be certain that we
17 are more than simply in name or in number a
18 medical home, that we are in fact in function
19 and dynamic and spirit, a medical home.

20 Because the structure is one thing;
21 the dynamic and the spirit is by far the most
22 important thing. But it's the most difficult

1 thing to achieve and the most difficult thing
2 to measure. In a brief moment, that's really
3 how we try to deal with the fact that
4 convenience is really a new word for quality,
5 and that ultimately, patient-centeredness,
6 activation, engagement, where our patients
7 really are equal partners in their care, both
8 administratively and also professionally. We
9 think that's important.

10 I appreciate the opportunity to make
11 this brief presentation. I believe in the
12 work that the National Quality Forum is doing,
13 and very excited about the opportunity to
14 watch some of our -- your development of these
15 measures.

16 We actually currently measure about
17 65 of quality metrics for NQF. We publicly
18 report on our website by provider name. This
19 is our sixth year to publicly report by
20 provider name on over 300 quality metrics. We
21 think that type of transparency is critical.
22 Thank you.

1 MS. PACE: Okay, thank you, and
2 we're going to go on to our next presenters,
3 and then we'll have a little bit of time, if
4 you want to come back and ask Dr. Holly any
5 questions. Susan and Amy are going to present
6 on some work they're doing with the PROMIS
7 measures, and Susan's going to start out with
8 just kind of orienting us to what PROMIS is,
9 and then Amy will talk to us about their new
10 project. So Susan.

11 DR. YOUNT: Great, thank you, good
12 afternoon. Next slide, please. I'm just
13 going to provide a brief overview of the
14 Patient-Reported Outcomes Measurement
15 Information System, which is known as 10 Peer,
16 funded by the National Institutes of Health
17 multiple institutes.

18 Initially a road map project, and
19 later a common fund project. This is a
20 cooperative group Network of 15 academic
21 institutions. The mandate for PROMIS was to
22 create self-report measures of health across

1 a number of domains that would be applicable
2 to a range of chronic illnesses.

3 The investigators knew that we could
4 never develop a set of measures applicable to
5 all chronic illnesses. So we had to pick and
6 choose as we needed to, and we adhered more or
7 less to the WHO structure of physical, mental
8 and social health for our over-arching
9 domains, our framework.

10 These are measures that we developed
11 for adults, for children, and many of the
12 child measures have parent proxy measures as
13 well. One of the unique aspects of PROMIS is
14 the methodology that was used to develop the
15 measures, which included mixed methods, a lot
16 of input from patients, from general
17 population individuals, as well as modern
18 measurement theory, which I'll just touch on
19 briefly.

20 Next please. So PROMIS has some
21 unique features among patient-reported outcome
22 measures, one of which is comparability, which

1 as I mentioned, it was designed to be
2 developed, to be applicable to a range of
3 chronic illnesses. So therefore, you can
4 measure fatigue and heart failure in COPD and
5 in rheumatoid arthritis, using the same set of
6 measures.

7 It's not what everyone wants to do
8 all the time, but it can serve as an
9 advantage. We also have a defined metric that
10 I'll get to a little bit later. All the
11 measures have been tested for reliability and
12 validity, and that process is ongoing.

13 There's a lot of flexibility in
14 terms of how the measures can be administered,
15 which I'll also go into detail in a little bit
16 and show you. So we have what we refer to as
17 static short forms, which are just paper short
18 forms of maybe 10 to 20 items, where every
19 individual will answer every item, and every
20 individual answers the same items as the next
21 person.

22 We also computerized adaptive

1 testing for many of our larger banks, and
2 people can customize their short forms,
3 because every item or most items, rather, are
4 calibrated and therefore you can take any set
5 of items and administer them as a customized
6 short form. Finally, one of our goals was to
7 make PROMIS inclusive to the extent that we
8 could. All PROMIS measures should be written
9 at about the fifth or sixth grade reading
10 level.

11 There are a number of translations
12 available. Most are available in Spanish as
13 well as a lot of other languages right now.
14 We have some unique banks in terms of physical
15 function, and as I mentioned, we have both
16 adult and pediatric measures.

17 Next, please. So this is just a
18 graphic display of the adult domain framework.
19 It's collapsed a bit. Some of these domains,
20 such as sexual function, gastrointestinal
21 symptoms, even dyspnea, they have many more
22 subdomains within them. So they're actually

1 many more measures than just the -- this is
2 just at the domain level, that fall within
3 physical, mental and social health.

4 Next, please. This is the pediatric
5 domain framework similarly organized. Next.
6 So in terms of the measures themselves, as I
7 mentioned, we have static short forms that can
8 be administered on paper or on a computer, an
9 assessment center which we'll touch on
10 briefly, generally 4 to 20 items.

11 The typical way of administering
12 these is that everyone answers all of the
13 items, and they answer all the same items. We
14 also have PROMIS profile short forms, which
15 are measures comprised of four, six or eight
16 items from among seven different domains for
17 adults, or six domains for pediatric.

18 The yellow highlighted items are the
19 pediatric domains and peer relationships is
20 strictly pediatric. So what you get then,
21 along with a single pain intensity item, which
22 is a zero to ten pain rating, you end up with

1 29, 43 or 57 item short forms, and you also
2 obtain a score within each of those domains.

3 Then lastly we have the PROMIS
4 global health measure, which is comprised of
5 10 items. Eight of the items can be scored
6 such that you get a physical health score and
7 a mental health score. This is used most
8 often when someone wants, as the name implies,
9 just more global self-ratings of health. "In
10 general, my health is," something like that.

11 Next please. So one of the really
12 unique features of PROMIS is that we offer
13 computerized adaptive testing. Where we have
14 domains that have banks, which are
15 collections, large collections of items, all
16 of which are calibrated, and these items then
17 can be administered adaptively if you have a
18 computer, and adaptive administration, I'm
19 sure many of you are familiar with this, but
20 it's simply algorithm that selects a middle of
21 the road item, and then the second item is
22 selected based on how someone answers that

1 first item.

2 So it's a branching algorithm that
3 achieves a high degree of precision with the
4 fewest items, and in general, people answer
5 four to six items per CAT, or in other words
6 per domain. I think our stuffing rule is set
7 at 12. So the most items they would answer
8 would be 12.

9 It does require computers. So there
10 is that drawback. It does not require an
11 actual CAT, however. The PROMIS metric is
12 based on a mean of 50 and a standard deviation
13 of ten. Sorry, got it in the wrong order
14 there. I'll go to the metric first, and the
15 current measures are referenced to the 2000
16 U.S. general population.

17 We have a project underway right now
18 to recenter it to the 2010 census, and high
19 scores reflect more of the domain or
20 construct. So high scores and fatigue mean
21 someone is more fatigued. High scores and
22 physical function means the person has better

1 physical function. So we chose the names very
2 carefully.

3 Right now, we have measures in over
4 40 domains for the adult set of measures, and
5 by the time the second wave of PROMIS ends
6 later this year, we should be over 50 domains.
7 Pediatric we have somewhat fewer, but we'll
8 have over 20 by the time all the sites have
9 completed their work, as well as parent proxy
10 measures for many of the pediatric domains.

11 Next, please. So again, advantages
12 to using PROMIS include improved measurement
13 because of the precision, which can result in
14 reduced sample sizes. Its adaptability and
15 there is a lot of flexibility in how it's
16 used, relatively low patient burden.

17 So you can administer a bank. I
18 think our fatigue bank has 95 items in it, but
19 the person's only likely to answer five or six
20 items out of that, to get a highly precise
21 estimate of their fatigue, comparability
22 across diseases are conditions, and it's

1 developed with NIH funds. So it is --

2 Next. I just wanted to mention this
3 briefly. I know it probably -- it doesn't fit
4 into the actual measure category, but one of
5 the things PROMIS also funded was assessment
6 center, which is a web-based study
7 administration platform, that enables the
8 creation and management of studies, as well as
9 the administration of the short forms and the
10 CATS.

11 You can go to assessment center, if
12 you'll go to the next slide, please. There.
13 If you go to asesmentcenter.net, that's also
14 where you can find out a lot of additional
15 information about the PROMIS measures.

16 It's where you can download them as
17 PDFs. You can look at the instrument library,
18 which is a library of measures currently
19 available, and you can set up studies there
20 obviously, and it also included the PROMIS
21 website for additional information, and I
22 believe that was my last slide. Yep.

1 MS. PACE: Okay, and now we'll have
2 Amy talk about a study that they're doing,
3 using some of the PROMIS measures as it
4 relates to some of our person-centered care
5 concepts. Amy.

6 DR. EISENSTEIN: Okay. So this is,
7 as you said, one of the studies that we're
8 doing using PROMIS to help target treatment
9 for patients with rheumatoid arthritis. If
10 you'll go to the next slide, please.

11 So the goals of the study are to
12 evaluate the added value of PROMIS to an
13 existing treat to target rheumatoid arthritis
14 treatment program, to use PROMIS to
15 standardize the patient-centered targets of
16 pain, fatigue, depression, physical function
17 and social function, and to individualize
18 these treatment targets in patient-centered
19 language, that retains valid and responsive
20 measurements.

21 So by personalizing the time that
22 Treat to Target patient-reported end points,

1 we were able to maintain adherence to patient
2 values, and by using PROMIS to do so, we
3 enable use of a common measurement framework
4 and standard score for tracking and reporting.

5 Next slide, please. To meet these
6 goals, we proposed these five objectives, to
7 add PROMIS assessments to the existing
8 electronic health record for rheumatoid
9 arthritis patients, in such a way that enables
10 individualized patient goal-setting, to
11 evaluate the impact of a Treat to Target
12 approach measured by -- measured clinically
13 and through PROMIS domains to individualized
14 patient treatment targets, to evaluate patient
15 satisfaction with the individualized Treat to
16 Target system, and to evaluate clinician
17 satisfaction with the Treat to Target system.

18 Next slide, please. There is a
19 little bit of background on the treatment to
20 target. The field of rheumatology has
21 experienced significant advances in
22 treatments, and an enhanced understanding of

1 optimal treatment strategies. Treat to Target
2 is an international initiative to define
3 rheumatoid arthritis treatment targets and
4 recommendations, to measure disease severity,
5 and encourage earlier diagnosis and optimized
6 treatment.

7 There is a widespread support
8 globally from the rheumatoid arthritis
9 community. Treat to Target has succeeded in
10 establishing international consensus in
11 defining targets that will be well-accepted
12 and applicable in daily practice.

13 Despite this, there remains a wide
14 heterogeneity of outcome expectations and
15 patient concerns, and patient-centered
16 outcomes have typically not been considered
17 when implementing Treat to Target strategies
18 in clinical care, and we know that patients
19 and physicians consider different aspect of
20 disease when making treatment decisions.

21 Next slide, please. So total will
22 be talking to like 120 patients who have been

1 diagnosed with rheumatoid arthritis. We will
2 include patients with low disease activity who
3 believe that, from their perspective, they
4 have not reached their personalized goal of
5 disease control. This will help to identify
6 a population in which there is disconnects
7 between the patient and the physician in the
8 shared decision-making process.

9 For those who are in high disease
10 activity at the start of the study, we seek to
11 determine whether the addition of the PROMIS
12 assessments will facilitate achievement of a
13 shared treatment target, and allow for
14 improved integration of the patient's
15 perspective into the steps required to achieve
16 that goal.

17 In terms of methodology, we'll be
18 talking with patients every three months over
19 the course of a year. Assessments include
20 clinical questionnaires, the PROMIS computer-
21 adaptive testing instruments, open-ended
22 quality of life items, and then the patients

1 will be asked to prioritize the PROMIS
2 domains, and that will be shared with their
3 physicians.

4 From there, they'll also be asked to
5 choose five of the items that are most
6 meaningful to them, in terms of their concerns
7 within their disease status, and those will
8 also be tracked over the course of the year
9 and shared with their physicians.

10 Next slide, please. So this is one
11 of only two studies that we're aware of using
12 individualized patient-reported outcome
13 assessment in rheumatoid arthritis. We're
14 actually working with the PIs of the other
15 study as consultants, so that we could advance
16 this area harmoniously with them.

17 This application of patient-reported
18 outcomes is both individualized and
19 standardized, which is only possible through
20 use of the IRT analysis and qualitative
21 clinical input from patients. That's it.

22 MS. PACE: Okay, thank you. So Amy,

1 maybe you could talk just a little bit more of
2 what this might look like in a practice
3 situation, because I think that will help
4 bring it to life a little bit, in terms of
5 having patients actually identify what
6 symptoms and then what questions from the
7 PROMIS. Could you just talk a little bit
8 about that, and then we'll ask the Committee
9 if they have any questions.

10 DR. EISENSTEIN: Sure, sure. So
11 that in terms of their using the PROMIS items,
12 their symptoms won't necessarily be specified.
13 They'll looking at each of those five items,
14 physical function, fatigue, depression and a
15 few others, and we have written up cards for
16 them which are an explanation of what each of
17 those domains, kind of examples of what they
18 are.

19 So for example, physical function
20 domain. We say "Physical function refers to
21 your ability to carry out activities that
22 require physical action. The activities can

1 range from daily activities, such as brushing
2 one's teeth to more complex activities, such
3 as household chores or yard work."

4 So they'll be given examples of each
5 of the domains just like that, and then asked
6 to choose which of the domains is most
7 important to their disease management
8 progression.

9 So from there, after they choose
10 which one of those is most important, they'll
11 be given a list of all of the items. Some of
12 the domains have closer to 20 items within
13 them, and some get up to 40 or 50 items.

14 They'll be asked to review those
15 items, and choose the ones that are
16 specifically most concerning to them. So now
17 some of the -- this allows the physician to
18 see, as an example here in the physical
19 function domain, some of the items could be
20 are you able to hold a plateful of food,
21 versus are you able to go up and down stairs
22 at a normal pace.

1 Some of the clinical insight from
2 the physicians doesn't necessarily get to that
3 detail or that understanding of where a person
4 is, in terms of what's important to them and
5 their quality of life. Does that help?

6 MS. PACE: Yes, thank you. Okay.
7 So we have a few minutes. If anyone has any
8 questions or comments for Dr. Holly or Susan
9 and Amy, Drs. Yount and Dr. Einstein, feel
10 free. Dave.

11 MEMBER deBRONKART: So first of all,
12 Dr. Holly, are you still on the line?

13 DR. HOLLY: I'm here, yes sir.

14 MEMBER deBRONKART: I want your
15 slides. I'm serious, and I mean to me, it's
16 the ultimate answer to all the people who say
17 it can't be done. I'm serious. I want to
18 spread the word through the patient community
19 as much as we can, because sometimes patients
20 can bring new ideas to their doctors. Who
21 knew?

22 DR. HOLLY: Oh absolutely.

1 MEMBER deBRONKART: No seriously.
2 I'm not being a smart Alec. Part of my --
3 DR. HOLLY: Oh no. I totally agree.
4 MEMBER deBRONKART: Part of my core
5 message of let patients help is not just
6 clinically, but in all sorts of things. I
7 loved all the presentations. Amy, I wonder
8 how did you settle on the RA? It's a field
9 that I know some people with that disease.
10 I'm just curious how you settled on it?
11 DR. EISENSTEIN: Well first, I will
12 say I actually joined this department after
13 the project was started.
14 But based on my understanding is
15 Northwestern participated in one of the -- in
16 the development with the Treat to Target
17 methodology. So they were already active in
18 that area when it came up that they were
19 lacking the patient input, and then just
20 through collaborations, this came up and was
21 developed.
22 MEMBER deBRONKART: So I ask because

1 are you aware that RA is one of the diseases,
2 if not the disease that is the worst in terms
3 of clinician arrogance and obnoxiousness? I'm
4 serious. No, serious. No. I mean it as a
5 real question, because I know some people who
6 have not mentioned your work, and I think
7 would be very interested to know.

8 DR. EISENSTEIN: You know, one of
9 the things that we are working with is
10 actually the physicians will be entering this
11 information into the electronic health
12 records.

13 So we are doing quite a bit of
14 follow-up with the physicians themselves, to
15 find out how much this benefitted them versus
16 the difficulty in terms of getting it entered
17 and tracking it over time. So we're certainly
18 looking at that.

19 MEMBER deBRONKART: I'm just
20 curious. So I'd love to know -- I guess
21 today's not the day, but I'd love to know what
22 the genesis was of settling on that particular

1 disease.

2 Because for instance, the famous RA
3 Warrior blogger Kelly Young, talks about how,
4 in great detail; I mean she's very, very
5 competent scientifically, talks about how what
6 the clinicians were taught to measure, aside
7 from not being what patients care about, which
8 is what you're talking about, but is also, in
9 many cases, demonstrably scientifically wrong.

10 I'll just -- in closing, I'll just
11 read a few sentences from a blog post by a
12 rheumatologist in Indiana named Larry
13 Greenbaum. "If your practice is like mine,
14 you probably don't bill for consult Level 5
15 very often.

16 It's the most expensive level of
17 care. A 75 year-old man came to me with RA,
18 didn't bring many records, but I spent a very
19 memorable hour with him. I charged him Level
20 5 for taking so much of my time, bad-mouthing
21 his previous doctors and incessant whining."

22 Down at the end, he says "He had a

1 deformity of his big toe due to a claw toe
2 surgical repair that had gone awry, and just
3 for good measure, he spent some time bad-
4 mouthing that doctor." The title of this blog
5 post literally is "Kiss my ...". The
6 Rheumatology News posted it and then after
7 patient complaints, they took it off the
8 index, but they would not remove the post.

9 So this is a profession that is
10 flagrantly disrespectful. So you can see.
11 You can tell the alarm bells that went off
12 here. I don't know who's in a position to
13 tell them to knock that crap off, if anyone,
14 and but anyway, so I'd like to talk more after
15 that.

16 MS. PACE: Right. But you would
17 agree that this is a great approach, of
18 sitting down with the patient and --

19 MEMBER deBRONKART: Oh positively.
20 This is exemplary.

21 MS. PACE: Right.

22 MEMBER deBRONKART: And I just don't

1 know if everybody in that patient community
2 knows that it exists.

3 MS. PACE: Good point.

4 DR. HOLLY: Yeah. There's another
5 -- this is Larry Holly. Another condition
6 that fits that same model and it's
7 Parkinsonism. PROMIS would be fabulous for
8 helping understand the desperate need for
9 autonomy and personal integrity, with patients
10 with gradually progressive disease, that can
11 still allow for a successful ending.

12 But rheumatology is -- RA is an
13 excellent example. Another would be, I think
14 would be Parkinsonism.

15 DR. YOUNT: This is Susan Yount. If
16 I could just interject. We were involved in
17 the development of another measurement system
18 called Neuro-QQL, which was also NIH funded,
19 which was developing very PROMIS-like
20 measures. I'm sure the Neuro-QQL community
21 wouldn't appreciate that I said it that way.

22 But they're using the PROMIS

1 methodology to develop measures for a number
2 of neurological conditions. So we do have
3 that as well.

4 MEMBER deBRONKART: Great.

5 MS. PACE: Ethan.

6 MEMBER BASCH: Just briefly. You
7 know, there's been a fair amount of interest
8 in innovating patient-reported outcomes and
9 care processes and to EHRs. It was, you know,
10 tied in, I think, to the topic of a prior
11 panel for NQF, and has been an area that PCORI
12 has been recently interested in.

13 I think that one of the real
14 challenges is around work flow, sort of
15 entrenched workflow, and it's really -- it's
16 just not built into the provider day to review
17 the patient-reported outcomes, to sign off on
18 it and to act upon that information.

19 So you know, it's on point and off
20 point to what we're talking about today. I do
21 think it's an important part of being patient-
22 centeredness in communication. But I think

1 that we have to bear in mind that it's very
2 challenging to get providers to look at these
3 things.

4 DR. HOLLY: May I comment briefly on
5 this? This is Larry Holly, because we -- beg
6 your pardon?

7 MS. PACE: Go ahead.

8 DR. HOLLY: We have really addressed
9 that issue over the last 14 years in our
10 customized EMR, because we believe that
11 quality metrics ought to be incidental to
12 excellent care. They ought to be collected
13 and reviewed, not as the intention of care but
14 the incidental.

15 As a result we have disease
16 measurement tools, clinical physician support
17 that providers utilize in providing excellent
18 care, coincidental to that and in the
19 background. That data is collected and
20 organized without the provider doing anything.
21 At the end of the visit, the provider can
22 review that, if he or she chooses, and can

1 then fill in anything they didn't think to do.

2 Invariably, over time, it just
3 becomes a natural part of their flow. For
4 instance, with congestive heart failure,
5 making sure you document the subjective and
6 objective evidence of fluid overload.
7 Initially, you might use the clinical decision
8 support, in order to make sure you deal with
9 those.

10 Ultimately, that just becomes a part
11 of your own the way you deal with patients.
12 I think it's possible, and unfortunately EMRs
13 are built by technicians who build it for
14 their specifications, and it's not built by
15 clinicians who build it in order to make it
16 easier for them to do it right, but not do it
17 at all. It is possible to do. I think we've
18 successfully done it and have demonstrated
19 that, and I think others can do it.

20 Everything we do is for free on our
21 website. We sell nothing and people can take
22 it and use it. But it is possible to do, in

1 the context of a busy clinical practice and
2 ordinary workflow.

3 MS. PACE: Okay. Why don't we start
4 here? Jennifer, Bruce, Ellen and Troy, and
5 then we'll close out this session.

6 MEMBER EAMES HUFF: Sure. I have a
7 question for either Susan or Amy regarding
8 PROMIS, actually a couple of questions. One
9 is could you say how widespread this is used
10 in clinical practice, to get a sense of where
11 it is or isn't being used, and then talk about
12 the facilitators for having this in use in
13 clinical practice, and some of the barriers.

14 DR. YOUNT: Wow, that's a good
15 question and a complex question. It's really
16 hard for me to answer the question
17 comprehensively, because we don't track who
18 uses PROMIS. Early on, we decided to make it
19 as freely available as possible without
20 barriers, which is also a big obstacle when
21 you present like this and then people ask
22 questions like that, and we don't have the

1 information to give you.

2 I know that Cleveland Clinic has
3 been using it for a few years in their
4 clinical care, and I actually don't know --
5 I'm sure there are other places doing it. I
6 just can't reel them off to you. I think one
7 of the facilitators is having the IT
8 infrastructure for the administration, and
9 maybe the scoring, the graphical displays and
10 so forth.

11 So I think that's a facilitator, and
12 not having that is potentially a barrier,
13 because then you're left with paper forms and
14 that's the age-old problem of how you score
15 them and get them into the medical record or
16 whatever. So I'm sorry, but that's the best
17 answer I can give you.

18 MEMBER LARSEN: So this is Kevin
19 Larsen. I can take a little bit of it. But
20 go ahead too. So under our measure
21 development contracts at HHS, we're developing
22 a whole suite of patient-reported outcome

1 measures. It's a really key area of federal
2 measures. It's a priority.

3 So because of that, we have to have
4 a lot of kind of field intelligence about
5 where these are deployed, so that we can know
6 how they work in clinical practice. So we
7 know that there are a number of organizations
8 and states, in fact, that use a lot of
9 patient-reported outcomes. Minnesota, for
10 example, has a number of patient-reported
11 outcome measures in their measurement domain.

12 They haven't incorporated PROMIS
13 yet, although in the meaningful use program,
14 we have a number of measures already in
15 federal programs that do incorporate PROMIS,
16 especially the PROMIS global assessment, in
17 current measurement statute.

18 We also are in the process of
19 discussing across HHS prioritizing PROMIS as
20 a primary instrument for patient-reported
21 outcomes, so that we have a coordinated free
22 measurement system around PROs.

1 So, you know, if I were a betting
2 person, I would bet that that's the kind of
3 thing that we would be likely to commit to as
4 a department.

5 MEMBER FORREST: Just briefly Susan,
6 Chris Forrest here. You might want to talk
7 about the Epic initiative.

8 DR. YOUNT: Chris, you can probably
9 talk about it better than I can. I know that
10 PROMIS is in Epic, in the electronic health
11 record. If an institution -- I believe an
12 institution has to have purchased that module.
13 I don't know if you want to add more, Chris.

14 MEMBER FORREST: I would -- I just
15 wanted you to be aware that Epic actually has
16 now created a patient-reported outcome module,
17 and embedded PROMIS measures into that
18 patient-reported outcome module. The PROMIS
19 Technology Center is working with Epic to go
20 from short forms, four or eight item
21 questionnaires, to computerized adaptative
22 tests.

1 The reason why Epic did this is
2 because of demand from its users. So the
3 advantage of having the PROMIS measures in
4 Epic is that they get standardized in terms of
5 the way they're stored in the database, and
6 also it just makes it easy for clinicians to
7 use.

8 There are a lot of other bells and
9 whistles which I can go into some other time
10 about the application. It actually is quite
11 nice.

12 MEMBER LARSEN: This is Kevin again.
13 Like I said, in answer to your question, we do
14 know of a couple of institutions, large
15 institutions across the country that are
16 deploying PROMIS as a routine part of patient
17 care delivery, though not in a specific domain
18 or framework. So for partners, for example,
19 a couple of their large practices have said
20 we're going to measure PROMIS at each and
21 every -- for each and every patient that
22 receives care in our system.

1 Align Health System in Minneapolis,
2 Cleveland Clinic, Northwestern, there are a
3 few that have done this in certain components
4 of their clinical practice, as a routine part
5 of the care delivery process, with the idea
6 that they can then get more sophisticated and
7 really be honing and targeting all of their
8 system to key patient-reported outcome.

9 MS. PACE: Troy and then Sally.

10 MEMBER FIESINGER: Okay. Thank you
11 Dr. Holly. Now I know where the slides my
12 boss is showing about how to publicly report
13 our quality measures came from, because I
14 recognize that screen from earlier this week.

15 So a couple of questions on PROMIS,
16 one technical. Can y'all run reports by
17 population, by patient group? Second, how do
18 you communicate this to patients and use it in
19 that form, and as a provider I'm thinking I
20 spend a lot of time doing Medicare physicals.

21 This gets at the core of what I want
22 to find out about these people, which is going

1 to be how do you present and organize it by
2 population, how easy is it to get the data
3 out, and then what do you do when trying to
4 communicate with the patients?

5 DR. YOUNT: If you're using PROMIS
6 with an assessment center, the data always
7 belongs to whoever set up the study. It's not
8 our data. So you can do a data export at any
9 time you want. It's really easy. You
10 literally just go in and click a button.

11 Then what you do with those data is
12 then up to you. Those aren't reports. That's
13 just the database, and I forget some of the
14 other aspects of your questions. I'm sorry.
15 Can you repeat them?

16 MEMBER FIESINGER: Yeah I guess can
17 I generate a report to show a patient? Can I
18 generate a report to show fellow physicians,
19 supervisors, hospital administrators, whomever
20 I want to show it to?

21 DR. YOUNT: On an individual patient
22 level, yes. We have these CAT reports that

1 are heat maps. So you can actually go to
2 assessment center or the PROMIS website and do
3 the CAT demo, and then see the report that
4 would be generated for the domain that you
5 select.

6 I'm not aware of any ability to
7 generate it for groups of patients, more than
8 one at a time right now.

9 MEMBER FIESINGER: Thank you.

10 CO-CHAIR OKUN: Hi, this is Sally
11 Okun. I'm calling from PatientsLikeMe. Thank
12 you for your presentations, and I just wanted
13 to let the group know that we actually are
14 also in collaboration with PROMIS researchers,
15 to work on --

16 We have a platform on our site
17 that's funded by the Robert Wood Johnson
18 Foundation. It's called the Open Research
19 Exchange Platform, and we're creating patient-
20 reported outcome measures with external
21 researchers and with patients collaborating
22 with us in that process.

1 One of the things that we recognize
2 is much of our work is really condition-
3 specific. So we're trying to benefit from all
4 of the great work that PROMIS has done with
5 some of more generic measures, where we can
6 find some alignment against the condition-
7 specific one.

8 So we're really hoping that the two
9 together will actually give patients a real
10 opportunity to give that kind of data, and
11 possibly get that kind of data collected prior
12 to a visit, and they can bring that in with
13 them as they come into this.

14 So the work -- integrating that into
15 the work flow could get more -- get a little
16 bit easier, from the patient perspective.

17 MS. PACE: Okay. Well thank you to
18 -- oh, Ethan, yeah.

19 MEMBER BASCH: Yeah. I just wanted
20 to make a quick note that, you know,
21 integrating patient-reported measures into
22 care is really just an improvement in the way

1 that providers already do things, right? I
2 mean as a provider, I'm supposed to talk to my
3 patients and do a review of symptoms and
4 understand what they're experiencing my, our
5 shared decisions.

6 We know that introducing patient
7 reporting into that process improves the
8 precision and the reliability, and the
9 management of those things being measured,
10 from multiple studies that have been done.

11 So you know, to me really the
12 argument here is that this is a way both to
13 make our current processes more patient-
14 centered, but also actually to improve, you
15 know, the precision of what we're already
16 doing.

17 It's not like we're reinventing the
18 wheel here. We're just trying to do what we
19 already do better, and patient-centeredness
20 helps us to do that. You know, the second
21 piece to that is it would be -- my
22 understanding is that a provider can actually

1 bill against a patient-reported review of
2 symptoms.

3 So in a scenario where an EHR has
4 the ability to collect information from the
5 patient, that goes to the provider. The
6 provider can sign off on that in the note.
7 That can actually be billed against, from CMS'
8 perspective.

9 MS. PACE: Okay. Well, I'd like to
10 thank Dr. Holly, Dr. Young and Dr. Einstein --
11 Eisenstein for sharing their work with us. We
12 really appreciate it, and thanks for taking
13 time out of your day to get on with us. Thank
14 you.

15 DR. HOLLY: My pleasure. Thank you.

16 DR. YOUNT: Thank you.

17 Small Group Work

18 MS. PACE: So what I'm going to do
19 briefly is tell you what we're going to do in
20 our small groups, and then we'll take a break
21 and move to our small groups.

22 So in your packet, you have some

1 instructions and the small group list, and so
2 I'm just going to go over a little bit about
3 what we're envisioning to happen in the small
4 groups. The goal is -- we've broken these
5 into four groups. We're broken into four
6 groups.

7 Each group will look at two measure
8 concepts. So Group 1 is going to do Concepts
9 1 and 2; Gene Nelson will be the leader and
10 one of our staff people, Karen Johnson, will
11 be with that group.

12 Group 2 is Concepts 3 and 4.
13 Michael Lepore is going to be the leader and
14 Mitra will be the staff person.

15 Group 3 is Core Concepts 5 and 6.
16 Bruce Leff is the leader and Camille from our
17 staff will be the staff person.

18 Group 4 is Concepts 7 and 8, and
19 Troy is going to be the leader and Wendy will
20 be the staff person. We'll tell you, Groups
21 1 through 3 will stay up here; Group 4 will go
22 to another room with Wendy on this floor, but

1 in another area.

2 So basically what we want to come
3 out of those groups with is some ideas of
4 measure concepts related to those core
5 concepts. We've identified a process that we
6 think will work, and the staff person can help
7 with this if there's any confusion. But I'll
8 just review it quickly.

9 So what we'd like you to do when you
10 go to those small groups is individually, and
11 you'll have some handouts specifically for the
12 group.

13 But basically start with looking
14 individually, reviewing that measurement
15 framework for the two concepts, and just
16 thinking for yourself, what are some measure
17 concepts that you think would be important to
18 measure for that particular core concept.

19 And again, you can think about, you
20 know, the core concept as it is or with
21 slightly revised wording. But I think we are
22 pretty well-understanding what the essence of

1 those core concepts are. We'd like you to
2 write that on a little post-it note, which
3 you'll have in your groups, and then if any of
4 those measure concepts are things that you
5 think would be applicable for the label idea,
6 to just indicate label on it.

7 Then we'll have you post those on a
8 paper, on a flip chart under structure,
9 process, outcome. Don't get too hung up about
10 that. If you don't know, just put it up
11 there, and then really to take five to ten
12 minutes to do that. So it's a fairly quick --
13 you know, I know you've all been thinking
14 about this for quite a while, and as we've
15 been sitting here and talking.

16 So to get those, you know, two to
17 three concepts that you think are really
18 important, that we should consider for
19 measurement. Then we'd like to have your
20 group discuss those, that people have
21 recommended, and we would ask the person who
22 suggested the measure concepts to describe it,

1 and to think about, you know again, describe
2 what you think should be measured.

3 You might think about what patients
4 would be included. Would it be all patients
5 or specific patients groups? If you have any
6 idea about data source or who's the entity
7 being measured?

8 We've had some of those discussions,
9 and again, these are not imperative, but if
10 you have some ideas about those to explain,
11 and then also why you think I should be
12 considered for a national standard for
13 performance measurement, or the label idea,
14 and to have discussion among your group.

15 Then you'll go through, after you've
16 discussed the suggested core concepts, we'll
17 ask you to vote on them within your group.
18 We'll give you some dots. You can pick your
19 top four in each concept, and those, you know,
20 the ones that have the most votes will be the
21 ones that hopefully your group agrees are the
22 most important to bring back to the larger

1 group.

2 Then we have some worksheets, to
3 just fill those out, so for when we report out
4 to the larger group. So again, I know that's
5 a lot to think about right now. Your staff
6 person can help clarify anything, and
7 certainly the leaders will facilitate the
8 discussion. Bruce.

9 MEMBER LEFF: So as a leader, I
10 definitely need something clarified.

11 MS. PACE: Right.

12 MEMBER LEFF: So it feels to me,
13 tell me if I'm -- sometimes this is jargon.

14 MS. PACE: Right.

15 MEMBER LEFF: So our 1 through 8 at
16 some level to me feel like high level domains
17 of measure. Is that a fair statement?

18 MS. PACE: Right.

19 MEMBER LEFF: If I'm hearing you
20 correctly, it sounds like you want us to get
21 to the level between a domain and an actual
22 measure. Sometimes those are called standards

1 or elements, the standards, quality standards.

2 MS. PACE: Well --

3 MEMBER LEFF: So for instance, if we
4 were -- if a domain was quality of life, so
5 not really one of our eight, but just quality
6 of life, a domain under that might be symptom
7 control, right, before you actually get to a
8 measure of, you know, improving depression
9 symptoms, right?

10 So are we in that middle range and
11 you're asking for constructs around those?

12 MS. PACE: So I think what, and
13 maybe we can -- if we look at the measure
14 framework, to just get some ideas. So for
15 example, your group will be looking at, which
16 ones, family and information.

17 So if the core concept is that, for
18 example, my family care partners include those
19 I choose, and their role is supported by other
20 care partners, you know, that would be kind of
21 the experience or potentially a patient-
22 reported experience outcome measure.

1 But are there other things that, for
2 example, are processes that support that? Are
3 there structures or systems that would support
4 the patient and family experiencing that core
5 concept? So you know, I don't know if there's
6 levels.

7 But it's really to start thinking
8 about if that truly is what the patient
9 experience should be in ideal person- and
10 family-centered care, the patient and family,
11 what would we do to assess whether that's
12 really happening and, you know.

13 So you know, the first obvious one
14 is the experience with care. But there may be
15 others, and that's what we want your group to
16 kind of grapple with.

17 MEMBER LARSEN: Yeah. I would say
18 in the measure development world, we call them
19 "measure concepts," you know. We're clear
20 that there's a whole process by which you go
21 from a general concept to a specific measure.
22 We're certainly not looking for a specific

1 measure, but something more than just a
2 framework or, you know, the --

3 So if I think about Dr. Holly's
4 work, it would be the number of or the percent
5 of times that a patient receives all of their
6 care on one day, you know. That's his --

7 (Off mic comment.)

8 MEMBER LARSEN: In the measure
9 world, that's not really a measure yet.

10 MS. PACE: That's really a measure
11 concept.

12 MEMBER LARSEN: That's a measure
13 concept.

14 MS. PACE: Because in the measure
15 world, then you have to get to the very
16 detailed data.

17 MEMBER LARSEN: In the measure
18 world, there's a 15-page document that tells
19 you exactly how to make that happen.

20 MS. PACE: Right. So you're right.
21 Some of this is terminology, and how deep you
22 get into measurement. But the point is to

1 really think about what could be measured or
2 should be measured. It's not really just what
3 could be measured; it really is what should be
4 measured, because if we focus on what could be
5 measured, we end up with measures we really
6 don't want or patients aren't interested in.

7 MEMBER DUBOW: So jumping ahead to
8 the endorsement process, we're going to --
9 these measures clearly are going to be exposed
10 to the criterion that is evidence. How much
11 in this space do we know about evidence for
12 structures and processes that support the
13 outcome that we're seeking?

14 Because I think that these are all
15 intuitively correct; they seem to have face
16 validity. But frankly I am not familiar with
17 the evidence that would meet the test of the
18 endorsement process. So what do we do about
19 that?

20 MS. PACE: Well, I think that's a
21 good point, and that's why I was bringing up,
22 you know, is there evidence that would say

1 that this rises to the level that you say we
2 want a national performance measure, which
3 means everybody should be measured against it
4 and be doing it the same way.

5 So that's where, you know, the
6 outcome of what we really want the person to
7 experience is probably first of all more
8 relevant to patients, and we have the patients
9 and patient representatives in each group. So
10 definitely do a test with them, as you're
11 thinking of these measure concepts.

12 But again, the other thing with
13 processes is that there's probably lots of
14 different ways to achieve the same thing, and
15 you know, there are system contexts, there are
16 patient contexts. So you know, I think it's
17 a good question and I think you're going to
18 have to grapple with in the group, you know,
19 whether process measures may not be the way to
20 go, especially in this space. But Kevin.

21 MEMBER LARSEN: I can tell you the
22 way we think about it at HHS, as we build and

1 prioritize measures. So that we definitely
2 hold a high bar for evidence and research.
3 But we also know that in the National Quality
4 Strategy there are some domains that are very
5 important, and if we have -- it's sort of a
6 Bayesian analysis.

7 If there isn't much evidence in that
8 area, we're willing to take more risk for some
9 measures with some evidence of face validity,
10 then we are on a new measure in an area where
11 that is heavily -- that has a heavy amount of
12 science and research.

13 So it's not to say that we don't
14 need some evidence. But we have a sort of
15 nuanced amount of evidence that we're willing
16 to do in these important measure gap areas.

17 MEMBER DUBOW: Okay. So I have to
18 tell you that there's -- I'm sorry. There's
19 a board committee now that's looking at the
20 next steps to flesh out the consensus process,
21 and already the question about scientific
22 evidence and what's good enough has bubbled up

1 to the top, no surprise.

2 But I think that we need to be
3 mindful of those challenges, because the
4 tension that happens at NQF, particularly
5 around endorsement, has to do with exactly
6 that, what's good enough. Are we driving
7 resources to processes and to structures, for
8 that matter, for which the evidence base is
9 unknown?

10 I'm okay with equivocal, but
11 unknown? I think we need to be very, very
12 thoughtful about this, because it's only going
13 to come back to bite us later. So I think we
14 have to be really careful about it.

15 MEMBER WALLING: I also just was
16 curious if we'd have the chance to comment
17 just on the framework in general too. One
18 question is just because process measurement
19 always has its limitations, but it also has
20 its benefits.

21 So for example in measurement, if
22 you only get outcomes back about your

1 patients, it's often difficult to figure out
2 how to improve those outcomes, whereas process
3 measures sometimes give more actionable
4 direction to what to improve, especially if
5 they're linked, the process and the outcomes.

6 So you know, if we're being broad I
7 would like to know that we're including as
8 many potential good areas for measurement, and
9 not cut out potential areas where there could
10 be a good impact on patient care. Does that
11 make sense?

12 MS. PACE: Sure. I think, you know,
13 and again, this is something that you'll have
14 to discuss within your groups. You know, the
15 other -- because we really want to identify
16 priorities and, you know, there probably are
17 hundreds of processes and structures that
18 would support person-centered care.

19 So you have to think about what do
20 we want to invest performance measurement in?
21 And so, you know, just because we may not want
22 something for a national performance measure

1 doesn't mean it wouldn't be very valuable from
2 an internal quality improvement, and figuring
3 out where you need to improve.

4 So I'm not saying to cut anything
5 off. I'm just saying that, you know, our goal
6 is eventually to prioritize and help identify
7 where to direct resources to develop
8 performance measures. If we have hundreds,
9 that's not going to be that useful or
10 feasible, in terms of accomplishing what we
11 want.

12 But definitely, you know again, each
13 person to really identify what they think is
14 most important, the group discuss those. You
15 know, when we come back to the larger group,
16 we'll be discussing them all of them as a
17 larger group, and eventually have to make
18 some, you know, prioritize and make some
19 recommendations that may fall into shorter
20 term and longer term.

21 So you know, right now, you know,
22 it's open. Think about it, and just really

1 discuss it in your groups. Yes.

2 MEMBER WALLING: Question. I know
3 the word "patient-reported outcomes" is often
4 used. I've seen patient-reported process too.
5 Are they -- how are we thinking about patient-
6 reported outcomes in terms of --

7 MS. PACE: When we had our project,
8 they were really patient-reported outcomes in
9 those domains of, you know, the functional
10 status, quality of life, symptom, symptom
11 burden, experience and health-related
12 behaviors.

13 So yes, you're right. There could
14 be a survey that says did you get your flu
15 shot, and that's patient-reported data, right,
16 and you know, I don't know that I need to say
17 anything more about that now. I mean it's not
18 off the table, but again, you know, with any
19 measure, you know, what's the best data
20 source, and do you want to, you know --

21 Just as an example, and this came up
22 in our patient-reported outcomes project,

1 there could be something very important to
2 patients. But if you don't -- if there's
3 another source of the information that is just
4 as good, then you don't have to ask the
5 patient to spend the time filling out a survey
6 about it.

7 So again, you know, we need to think
8 about, you know, the burden and who's the
9 authoritative source for any particular
10 information.

11 MEMBER WALLING: Just to clarify,
12 the example I'm thinking of is, for example,
13 process measures on whether patients feel that
14 their symptoms are assessed and managed in the
15 way that they want them to be managed.

16 So it's not -- so it's a patient-
17 centered measure, that we actually have looked
18 at it in medical records and patients, and you
19 get slightly different, you know, results.

20 MS. PACE: So we don't need to get
21 hung up on whether it's a structure, process
22 or outcome. You know, obviously if it's

1 evident to note that, but you know, the main
2 thing is really what should be measured given
3 our discussion about what is person- and
4 family-centered care. Okay.

5 So we'll take, you know, if you need
6 to take a break -- yes, Dave.

7 MEMBER deBRONKART: So tiny but
8 vital one. You just triggered something. I
9 hear so often people say that we could ask did
10 you get to say everything you wanted to say,
11 right, and that could include -- I mean I know
12 of people who had five things they wanted to
13 bring up and/or conditions, and they only got
14 to do two and the meeting was shut off.

15 Or were you interrupted a lot? You
16 know, the famous 17 seconds between
17 interruptions. Is that all fair game?

18 MS. PACE: Yes.

19 MEMBER deBRONKART: And I don't even
20 know if that's a process or did you --

21 MS. PACE: No, it's fine. It is
22 totally fine, and I think -- I really think

1 that Dave's challenge to think about this, you
2 know, what's the simple question we could ask
3 patients, is very important for all of the
4 groups to be thinking of, and yes, that would
5 totally be fair game.

6 CO-CHAIR OKUN: Just one other
7 clarification I'd like to make, because I
8 think that's a really good point, and that may
9 apply to one concept but maybe not another and
10 that sort of thing. So I guess -- and then
11 we're not necessarily then charged at all with
12 thinking about whether that -- there's a
13 measure that exists for that yet.

14 That's where you then take the
15 things that we say. This should be part of a
16 patient, family centered care concept. We see
17 it should be in this particular concept that
18 we've come up with, and then you're going to
19 be taking that and sort of testing that
20 against what exists already to measure it, or
21 if that's a gap we've identified.

22 MS. PACE: Right, absolutely. We

1 know that some of, you know, the CAHPS
2 measures actually have -- or the CAHPS survey
3 actually have a lot of individual measures.
4 In the measurement framework, we identified a
5 few that related to the core concepts, and
6 there's, you know, many others.

7 So we can look to see if there's
8 something that's already measuring that. But
9 the idea today is really to start thinking
10 about what should be measured in this space,
11 and then we can see if there's already
12 existing measures which will help us also.

13 MEMBER FORREST: I'm going to go
14 back to a comment I made earlier. So if you
15 take a domain broadly speaking, like respect
16 and dignity, there are -- that can be fleshed
17 out and there are ways of measuring that.
18 That's at the experiential level of the
19 patient.

20 If we only focus on that though, we
21 are going to be missing the measures of the
22 system that enables that. I wonder when we're

1 going to get to that, for example.

2 MS. PACE: Right, and if you -- now,
3 I mean because that would be the structural,
4 the system measures. So if there are things
5 that really are system-related, that really
6 support that happening and you know --

7 MEMBER FORREST: So we should be
8 thinking about like a driver diagram. So
9 there's -- ultimately in this person-centered
10 care, respect and dignity is one of those
11 components, and then there are system level
12 domains that relate to that.

13 MEMBER LARSEN: Yeah. I would say
14 absolutely. You know, one of the measures
15 that I did in my health system was what
16 percent of a nurse's shift did she spend at
17 the patient bedside, versus anything else. So
18 that's a structural measure or a process
19 measure that absolutely drove patient-centered
20 care.

21 We were -- focus was one of our
22 number one priorities for inpatient nursing,

1 to get the nurse in the patient room talking
2 to the patient as much of her shift as
3 possible. So I would say those structural
4 measures are absolutely on the table.

5 MEMBER BASCH: So there could be
6 multiple measures, some could be patient-
7 reported, some are process measures for each
8 of these individual domains or concepts.

9 MS. PACE: Exactly. So I know
10 that's kind of fuzzy, but we'll work with it.
11 I know you all have great ideas, and we'll
12 trust you to work this out in your groups, and
13 given the time, what we're going to do is not
14 try to do report-outs today, because we want
15 to give you enough time.

16 So we really will spend the rest of
17 our day until our adjourn time is 5:15 in your
18 small groups, and then we'll do report outs in
19 the morning and just our schedule tomorrow
20 some. But we wanted to give you enough time
21 and not have you hurry.

22 So with that -- okay. So Group 1

1 will be at that end of this room. Group 2
2 here. Group 3 in the back, and then Group 4
3 is going with Wendy to another room, okay.
4 All right, thank you.

5 And operator, I guess we should --
6 Wendy, I guess we should just go ahead and
7 close the webinar. For those on line, we're
8 going to go ahead and close the conference
9 call, since we're not going to reconvene as a
10 large group, and we will also end the webinar
11 at this time.

12 (Whereupon, at 3:30 p.m., the
13 meeting was adjourned to small group session.)
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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: 04-07-14

Place: Washington, DC

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