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

AGENDA

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

9:07 a.m.

Welcome and Introductions

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

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

So just, you know, kind of where you're coming from, as we go into this meeting and this topic. We have, you know, a whole set of panels and presentations and discussion groups for us today. But we thought it would be good for everyone to have a chance to just kind of lay out their most important things for all of us to understand and share where we're coming from.

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

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

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

CO-CHAIR KOTAGAL: Good morning. I'm Uma Kotagal. I'm a pediatrician at Cincinnati Children's and direct the transmission work there. I'm a health services researcher, and we have been pursuing and thinking a lot and learning about patient-reported outcomes, how they've changed how we do our work, how they've changed how the team functions. So I'm delighted to be here.

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

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

So being here and starting to think about patient and family, person- and family-centered care, and how we can begin to measure that and then measure the performance against it is incredibly important to me.

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

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

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

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

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

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

So I think it's very important in

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

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

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

I would note that as both a clinician and as a clinical investigator, I frequently find myself frustrated that both the care that we deliver and the way that we conduct research is not patient-centered particularly. We do not take into consideration the perspectives of patients.

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

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

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

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

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

It turned out that when you followed people, they had really dramatic impact to changes in health policy. From the window of health services research, where you always just look at claims or you look at a specific site of care.

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

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

MEMBER deBRONKART: So I'm Dave deBronkart, known on the Internet as ePatient Dave. For those who don't know it, the "E" stands for Empowered, Engaged, Equipped, Enabled, and seven years ago this month I was dying of Stage 4 kidney cancer, and along the way, in addition to getting great medical care, I did everything I could to help myself via the Internet, connecting with other patients and so on.

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

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

I have -- Ted talked in a book titled Let Patients Help. I don't assert that even well-informed patients are oncologists. I'm also something, having worked in IT in most of my life before this, I'm something of a bugger about data quality. Just five years ago this week that I wrote a blog post about my medical record containing garbage that ended up on the front page of the Boston Globe, which led to me testifying on meaningful use and all kinds of things.

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

MEMBER NELSON: Good morning. Gene Nelson. I'm at Dartmouth Institute and Dartmouth-Hitchcock, and work in the Population Health program there. Very, very interested and committed to finding ways of improving and innovating health care and the outcomes that people want, very interested in the design of full health systems and front line systems that put the individual patient person at the center, and that everything flows from that, and the design of information and measurement systems actually support care as it's delivered and people living, their health and health conditions.

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

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

MEMBER FIESINGER: I'm Troy Fiesinger. I'm a family physician in Houston, Texas, currently residency faculty. But as I think of my experiences, I have worked in real health screening clinics, I've been in large multi-specialty groups, done QI, been medical director of the FQHC.

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

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

It's not patient-centered, dirty little secret, and I'm in a Level 3 PCMH. We spent a huge amount of time and effort to become one, and we're not there yet. We're hindered in frustrating ways by our own biases, misconceptions, learned behaviors, and it's been frustratingly challenging to take a bunch of really innovative, open-minded people and get them to change.

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

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

So how do I merge all that stuff

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

(Laughter.)

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

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

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

MEMBER JHINGRAN: Hi. This is --

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

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

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

My interest in this committee was primarily because for about almost 15 years, I was very inward-focused. I focused on patient-reported outcomes, quality of life measures which were needed for pharmaceutical companies and for our research programs.

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

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

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

When I decided to do that, I really wanted to make a difference. I was in managed care for a while, during a time when people felt that managed care was the devil.

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

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

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

All those who are not in the know I think have much more difficulty, and even us at times, who think we know things or have connections, can't really seem to get it. So that's my background and why I'm passionate about this work.

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

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

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

You know, we're all patients at one point and we're all family at one point of somebody else who is a patient, and it's just common sense. There are many areas of the world that don't quite see things that way.

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

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

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

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

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

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

The second dimension is on family

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

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

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

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

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

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

I think the other piece is thinking

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

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

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

My work has focused on health care delivery for older adults with complex health needs, and who often rely on a family member to navigate the health system, and thinking about the patient who may be homebound or may not want to be involved in decision-making. Oftentimes, they delegate decisions to a family member.

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

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

I'm really delighted that this committee has decided to think about patient- and family-centered care, and to take on the challenge of thinking about when family engagement may be different than patient engagement, and thinking about the potential of improving quality of care by better preparing family members for their involvement.

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

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

Our interest -- and I'm also chair of the Consumer Council for NQF. Our interest is in developing tools that would strengthen the patient's voice in the redesign of the health care system. There are a lot of very powerful institutional actors, who are weighing in on what the health care system should look like, providers, insurers.

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

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

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

MEMBER LEPORE: Good morning. My

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

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

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

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

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

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

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

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

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

So I think at the heart of the work that we do is really to be patient- and family-centered. That's really important and the core of our advocacy work, and how it plays out in measurement and being patient- and family-centered.

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

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

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

I think on another note, some of my

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

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

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

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

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

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

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

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

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

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

So I'm Lisa Latts. I am influenced by training with subspecialty in high risk pregnancy care. But my background is in the payor world. I worked for WellPoint for many years, focusing on quality improvement, quality measurement, patient safety, as well as delivery system transformation and how do we do quality from an innovative perspective, looking at how we change the delivery system, and as well as have spent a little bit -- too much time as a patient over the past few years. So I have a perspective there as well.

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

So I think that's something I just want to make sure is thought through. So I will hopefully be able to do as much as I can on the phone today. So thank you.

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

Setting the Stage

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

Certainly, my background has been community care and community-based care for most of my career, and I think it is marginalized often when we think about how to do we measure that and good quality care there, and I think we'll identify certain numbers of gaps that we can probably think about filling.

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

FEMALE PARTICIPANT: No.

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

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

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

You know, we're sort of told that these things are coming or they're there, and yet we may not be seeing them. So if we're not seeing them and we're not aware of them, or if we have a family story that's helping us to illuminate where those gaps are, that insight is really going to be helpful here today, and then prioritize opportunities for person-centered care, performance measurement over the short and longer term. So I think we can't solve everything here in these next two days.

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

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

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

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

We'll have an opportunity for public comment this afternoon, and then we're going to actually have some time to spend with each other, really thinking through the core concepts, and starting to put some real hard challenges to them, to suggest whether or not these are things that we can actually start to identify ways of being able to measure first, and then measure the performance against.

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

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

We'll have again some more opportunity for public comment, and then ultimately break down into some small groups again, and really try to bring back to the NQF some meaningful content for them to take then to the next step. You can go on to the next one. I think that's fine.

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

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

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

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

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

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

The next slide please. So the scope of this project, as many of you will recall, when we started this, when the landscape was laid out for us early in this by Mitra and Karen, it was really sort of taking an opportunity to look at the domains of quality that IOM had laid out, as well as the National Quality Strategy priorities.

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

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

One of the things that I think was really interesting to me, and Uma might comment on it at some point later, is that on the Montreal model for this inter-professional education, they actually moved from having the patients in the center to having the patients as part of the whole circle, so that everyone is sort of part of the same team.

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

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

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

CO-CHAIR OKUN: We know each other well.

CO-CHAIR KOTAGAL: And have come to know each other well. I, like Sally, was stuck by the passion and the personal stories that have brought each of us here, and I know in the call, we experienced a lot of that passion and attention to detail and so on.

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

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

But when we're thinking about the organization level measures, we're thinking about something rolled out, aggregated. That helps us think about the measurement. I think when we begin to think about measuring patient- and family-centered care, the patient reported outcomes become really important, and the prior work of the NQF on patient-reported outcomes and performance, has used this definition of the patient-reported outcomes as any report on the status of the patient or a person's health condition, health behavior, experience with health care that comes directly from the patient without interpretation, filtering of this by somebody else, that says "No, I think is really what they meant, even though they didn't say it," that sort of modification.

The three domains that I think we're interested in, as we think about this -- the four domains, the first is obviously the health-related quality of life or the functional status; the symptoms and symptom burden, pain, fatigue, experience with care specifically, communication, decision-making, which is what we're focused on a lot, and then health behaviors and how the patient reports and thinks about their interpretation of it.

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

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

If we get to the next slide, I think our task is to identify, you know, the measurement framework and the task more clearly this afternoon, but a couple of comments for us to think about, as we think about definition and core concepts.

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

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

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

So as we think about this, the task that we'll be thinking about really tomorrow is, you know, we'll hear more about this. But here are a few questions I wanted to sort of leave you with as we're thinking about this.

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

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

Project Overview and Related NQF Projects

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

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

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

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

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

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

So we look to the rest of you to keep us honest, and tell us when we're using terms that aren't -- you don't understand are that are insidery, and we also really -- help us to be open and thoughtful to the new ideas and the things that really make sense, because again we come with a long legacy of internalism, and we want very explicitly here to not -- to not have this look like everything else.

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

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

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

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

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

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

I got into health care as a

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

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

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

When my brother was seven, he had a set of measuring cups that he had measure all of his food and there was a scale next to his plate, and we had time all of our meals when exactly we would have them, and we would measure the food by how much it was. He couldn't have more or less than that. My job as his brother was to keep track of all this, and we never would dare change any of this without calling the doctor.

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

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

They made a very conscious effort, it's something I've been following as a physician, that I'll meet with patient educators. So previously I was a hospital administrator. I would meet with and study a lot of health literacy, and I always would go for the diabetes educators, because everybody else still had this notion that what our job was was to spoon feed patients in exactly how to do things.

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

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

MS. PACE: All right, thanks. Mitra is going to tell us a little bit, just a quick overview of the projects, since you've heard that, and then some things about related NQF projects.

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

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

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

So once the whole committee was formed in January, the committee again convened at that meeting, and we presented the draft, the finished core concepts that were based on the foundational works of the NQF priorities, as Uma and Sally alluded to, and after the web meeting, again we conducted a survey to further refine those core concepts and definitions, and also receiving additional input from the co-chairs.

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

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

During that public webinar, the recommendations from the three committees under this project, care coordination, workforce and person-centered care outcome. We'll be reviewing the recommendations and just pushing out information to the public, and encouraging public to submit comments on the draft report, via the commenting tool on the NQF website. Lastly, the final report will be due on August 15th.

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

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

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

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

So the other project is the endorsement project, and NQF and the respective committee will be looking at measures for endorsement to build NQF portfolio in this area, person- and family-centered care, and actually Karen Pace is leading that effort.

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

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

CO-CHAIR OKUN: I suppose questions on this and anything that's been brought up. I think what we'd like to do is sort of before we take the break, to see if there's any burning questions or anything that's on someone's mind that we, you know, really need to get out and pay attention to, or that you just want to say sort of setting the stage.

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

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

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

Whatever we do, for all the micro-measures, my view is that every single visit ought to end with the simple question how was this for you? Did you feel like you were taken care of, right, and that that is like -- I mean if that isn't the ultimate patient-reported outcome, I don't know what is.

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

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

They produce the test that everyone has to pass before they can be called an M.D., and this woman got this achievement award because she's been working on whether the test items in that exam correlate downstream with how well the doctor actually does in practice. She had this great diagram that I'm going to try to get the slide, that said the course of a disease, without treatment, is like this.

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

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

One final thing. Sometimes somebody

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

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

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

So how do we pull it all together, and is there any cross-fertilization between the workstreams, to get a better sense of what others are thinking relative to what this team is?

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

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

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

But that's at least from the federal side, who's asking for some of this work to be done by NQF. That's part of the way we're thinking about it.

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

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

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

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

So I just know one of my efforts is to make sure that those that are at the sharp end, especially clinicians who are caring for patients, don't somehow get held accountable. So when we say "held accountable," I just kind of want to leave that out there as one of those things to remember. That is a good thing, but it can also have unintended consequences.

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

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

I then took the Department of Health Care Management faculty and gave them the same exercise, and their ages ranged from about 35 to 80. They put their doctor in the middle, and then they arranged the doctors, the health care facilities around them.

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

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

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

So what's missing for me around this is the connection to better outcomes, that matter to me as patients, that matter to me as family members. So if we're really wanting to get to an operational set of measures, then great. I think we're well along the way. We're well-calibrated.

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

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

There's probably a subset of those that we can actually measure, and then I think it's very, very important to think about the subset of those that you can measure well, that will actually have an influence on an outcome.

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

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

Our health system probably as being a high reliability organization, drives all events to zero. CEOs at the hospitals are rewarded or fired based on their performance along those lines. Physicians, you know, modify their behaviors.

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

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

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

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

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

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

So I think we always have to think

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

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

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

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

MEMBER FIESINGER: We say burden.

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

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

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

We have a whole host of purposes for measurement. So I think we need to think about what we can measure, and we're focusing today on patient-centered family-centered care, and that's what we need to look at. I think that it's useful to think whether these -- how these measures fit into the large and cold.

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

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

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

CO-CHAIR OKUN: So I just want to

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

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

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

We're really talking about

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

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

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

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

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

So you know, for either a provider or an administrator who wants to say "Look, you know, we have to get patients into the room sooner. We have to train our medical students and residents not just to talk at our patients, but to listen to them. We have to use measures that help us to understand patient's decision-making preferences," etcetera, etcetera, whatever it's going to be from the bottom up.

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

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

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

Definition and Core Concepts

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

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

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

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

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

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

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

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

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

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

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

So an approach to planning and

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

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

So the first one is that my care partners strive to know me as a whole person, to take into account my priorities and goals for physical, mental, spiritual and social health, and I think this morning we covered some of that during our discussions.

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

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

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

My family care partners include those I choose, and their role is supported by other care partners. So again, I'm in the driver's seat. I'm going to decide how this happens. So let's take a few minutes and think through that.

(Off mic comment.)

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

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

Then communication with and among my care partners is honest, transparent and coordinated across settings and time. So these are the core concepts I think that we are talking about when we're thinking about person-centered care, and with that, let's open that for some comments or questions.

FEMALE PARTICIPANT: Karen, you may have something.

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

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

MEMBER NELSON: Well thanks for this invitation. Karen and Mitra asked me to focus on that first concept. "My care partners strive to know me as a whole person, and take into account my priorities and goals for physical, mental, spiritual and social health." That's a pretty tall order.

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

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

Molly was fortunate to establish a primary care relationship at Dartmouth Health Connect, a practice whose explicit mission is bringing humanity back to health care. She presented for the first time in a state of extreme mental anguish due to physical and emotional pain. She found an immediately comforting environment, and a tightly integrated care team.

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

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

This specialist encounter proved

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

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

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

Molly continues to work on mental

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

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

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

Second, as you saw there's a care team. There's a physician, there's a health coach, high school graduate generally with special training, and a personality that is right for the job. There's an embedded behavioral health specialist, and then they run these processes, these routine things.

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

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

Finally, and fourth, there is systematic and repeated use of patient-reported outcomes. At the end of every visit, a person is sent an email, and asked three questions. Would you recommend us, scale 1 to 10; how did we do in providing your care today; any ideas for making care better.

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

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

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

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

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

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

Sometimes Darryl has difficulty

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

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

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

So the first thing they did was to repackage his medications that he used in the inpatient setting for use in the outpatient setting. So when he went home, he had his medications, because the commonest thing happening was Darryl was coming back three weeks later, because he hadn't filled his medications.

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

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

I think the third thing they did was to find a local pharmacy in the inner city that would deliver the refills to Darryl, because once they were discharged home, Darryl's problem was not getting his refills filled, and this pharmacy does deliver and is linked to the Medicaid database, and allows his team to know that Darryl did get the medications.

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

When we sorted the zip code, we found that there were actually landlords in several buildings that were not sort of taking care of their buildings. Then, you know, working with the school nurse, so that when Darryl is in school, the school nurse knows and can intervene, can recognize and can reinforce it.

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

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

Then for kids, the working between different settings, not really just thinking about the health care system. Back to Chris' comment, really thinking about the broader system for kids, where they live and what does it take for Darryl to be healthy and be able to play basketball and grow up to be a policeman.

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

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

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

So Mr. L was diagnosed with advanced non-small cell lung cancer about six months ago, and is currently on an inpatient medical ward for pneumonia. He has been followed by his outpatient oncology clinic, and has been receiving chemotherapy. This chemotherapy has been held while he's in the hospital.

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

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

Inj the hospital, he's been given fluids and antibiotics, and some doses of morphine. His fever, pain and shortness of breath have improved during his three-day hospital stay. So at 6:00 a.m. on his third day in the hospital, Dr. M enters into the room without knocking and wakes him up to ask him about his symptoms.

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

So this list is not an exhaustive list of some of the best practices that may represent this core concept, and it may have some overlap with some of the other core concepts. But providing information and support in a timely fashion, tailored to a patient's needs of readiness; providing common courtesies such as knocking and privacy; responding to emotion with empathy; and providing high quality communication and psychosocial support; being aware of the patient's needs including social, spiritual and economic needs; and identifying needs that can be made by medical or community resources for the patient and/or the family.

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

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

He's been working with a social worker, who is part of his outpatient team, who has been helpful in providing resources that have limited financial strain and a chaplain has also worked with him with some of his spiritual concerns and helped to refer his son to a support group, which has helped the family a great deal.

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

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

So this time the doctor says "I know

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

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

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

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

I reached out to several Planetree hospital members for examples about this, and what I found was that there was a lot of overlap across many of the concepts, and I really wanted to keep it narrow on this concept, and the overlap. So I said okay, well it's actually a full culture of change has happened in these places.

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

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

She is a beautiful 68 year-old, vibrant woman, as I've been told, and the paternal side of her family has the early onset gene for Alzheimer's. Half of her siblings have already manifested symptoms, including her 49 year-old brother. Her father died of Alzheimer's, as well as eight of her 12 aunts and uncles.

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

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

So there's this really, I think,

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

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

MEMBER WOLFF: So the concept that I was asked to talk about is "My family care partners include those I choose, and the role is supported by other care partners." So this concept in my mind reflects the notion that some patients navigate health care processes in a broader family context, and that in the ideal state of a patient who has capacity and the support of family, their patient wishes should drive decisions about family involvement, and the care providers would ideally respect and support patient wishes, both to include as well as exclude family members.

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

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

In terms of a vignette, I turned to a resource which is a wonderful book by Susan McDaniel called Family Oriented Primary Care, and there are -- this book has many, many examples and resources across the life course. The examples in the book largely all reflect this common theme of proactive health system involvement, to support the patient and the family member.

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

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

So a new patient, Mr. Samuel, is a 30 year-old Romanian bricklayer, who was prescribed medication and a low salt diet for his hypertension by Dr. L. Mr. Samuel's parents, with whom he had emigrated and now lived, had doubts about the efficacy of medical treatment. They questioned the medication, and felt the diet would mean their lifestyle would have to change too.

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

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

In the meantime, his blood pressure remained elevated. The doctor soon recognized the situation and invited the patient's parents to come in with him. He explained their son's hypertension and the rationale for the treatment plan. He enlisted their help, clearly indicating they could bring about some change for their son.

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

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

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

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

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

I said could you please write this down for me, because I am anomic. I won't remember any of your names. I am anomic. I cannot remember names, I can't remember names of medicines that people tell me about quickly. I said please write that down. He said don't worry; we have this wonderful thing called EPIC. It will be in your after-visit summary.

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

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

She emailed me last night. I was getting better, now I'm not better, you know. What now? Email back and forth. This is really not ideal for me as the provider, and we're sorting it out, and I'm sorting it out still. But she appears to be getting better, which is good.

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

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

How do I communicate with her? She doesn't want to be contacted with my by phone. Only wants to see me when I make a visit to the home, and then only wants to get new information on how to give the medicines by me writing on the bottle itself, which by the way you can only reconcile medications with the bottle in hand. Editorial comment.

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

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

Some issues are not easy to address. So for instance, in that long text, the word "costs" appears. It is really hard for anyone to know what anything costs in health care, right. I can say I think that thing is going to be really expensive, but I would say even within health systems, you don't know if the colonoscopy done, in which building within a health system might have a factor of five or ten in terms of difference in cost.

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

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

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

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

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

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

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

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

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

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

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

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

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

Instead, I went online within one minute and found oh yeah, that crusty thing on my scalp. So I was more compliant with less utilization of resource by the practice. It can be done, and then finally a couple of years ago, I was doing a series of speeches in Spain, and at one dinner meeting, somebody said "Oh come. You have to meet Dr. Cassado." Dr. Cassado tweets to his patients when he's running behind schedule, right.

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

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

"Nothing drives change more than the

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

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

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

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

FEMALE PARTICIPANT: It's too late.

MEMBER FIESINGER: I know. So this is my experience from my family's horrible, terrible year, where we started the year with my mother having emergency bowel surgery for bowel obstruction at New Year's, having post op delirium. She's hard of hearing, she has an anxiety disorder. You can imagine the things she put together in her brain from what the caregivers did and did not say.

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

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

So I got first responders were a dentist and a radiologist, who were out walking that day. My wife came, called EMS, and here's the good thing. They said which hospital do you want to go to, because I told him who I worked for and I could chose two ones, the one where I practice, which I know is not very good at trauma, doesn't have enough people on call. I said I'll pick the University hospital. It's a Level 1 trauma center.

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

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

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

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

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

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

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

We have, you know, between us like 30 years' experience in health care, ten years of graduate education. I thought if we can't figure this out on a good day, Lord help everybody else. So I'm discharged, four months of hand therapy. You know when I say you know, I don't really want to come to the medical center, the traffic is ridiculous, parking costs too much. Okay, we'll find a hand therapist out where you work, so you could go after work. That was good communication.

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

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

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

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

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

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

So the whole aspirin issue was very frustrating. I couldn't get an answer outside of no, and they wouldn't even make me an appointment. Like I'll come in and talk to you. That's fine. So when I said and asked my doctor to send me to a different neurologist, I got in, was seeing the one that I wanted to see.

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

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

But having stuff go on and off and people contradicting orders and knowing it's going on, as a physician it's frustrating. As a patient, I'm trying to be calm about this, but this really stinks. You know, just the paramedics saying look, we can't give you drugs, but you can cuss all you want. Okay, at least I know, because this ride -- this five minutes is really going to hurt when you guys hit a pothole, because when you have fractures, anything that bumps you is bumpy to your bones.

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

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

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

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

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

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

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

But it's challenging to do it right, and these weren't -- clinically, these were very good physicians, but communication was all over the map. So I think, you know, your question of asking how was this visit for you is a good one. Being aware of impairment. I mean I basically was impaired the whole time, from just opiates and sleep deprivation.

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

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

MEMBER deBRONKART: A real quickie. I had the same thing happen when I broke my leg, because of my cancer, and we had an ambulance ride down I-93 into Boston at pothole season. I mean I had morphine that the medics had given me, but still I ended doing a modified Lamaze thing in the back there. The driver would say "here comes another one," and I'd go (breathing heavy) to get through it.

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

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

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

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

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

MEMBER LATTS: Okay. I just wanted to emphasize sort of a theme I heard in several of the vignettes, but I wanted to let you know what's so important from my own personal experience, which is really meeting people where they are, from an empowerment and an engagement perspective.

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

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

I think that that constant reassessment needs to take place and needs to be measured, so that even if we think we know how activated or engaged someone is at an one point in time, that changes, depending on where they are in the health care spectrum, but also what else is going on in other parts of their life, who else is available to help them make decisions, etcetera.

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

CO-CHAIR KOTAGAL: Okay, Bruce.

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

You know, I don't know if it argues

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Either we give patients full control, come what may, and he actually talks about that a little bit and says that, you know, he doesn't think it's going to be as bad as we all worry about. Or we have a more pragmatic approach, that takes into account everything else that's happening in the health care system, like the fact that you are being measured and paid on the basis of what happens, and that you are held accountable for the decisions that you make.

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

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

I mean nobody could disagree with

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

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

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

But that's because you're

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

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

So I think -- and certainly I can remember all the time in practice it's Friday afternoon. I'm trying really hard to care about your depression, but I'm sorry, I want to go home, and I wish you had just a strep throat. That's just the reality of physicians' lives, of nurses lives, of everyone's lives, not to be aware of that global context. That's not a measure, but I think an unintended consequence.

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

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

You know, my son has ADHD. What do we want? We want to not get calls from the school every day. That's what we want. We want him to actually get into college. We don't care about scores. The scores are a means to an end, but our real goal is that, and finding out for each what that is and put it as the chief complaint.

CO-CHAIR KOTAGAL: Yeah, Lori.

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

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

So I wouldn't want this group to let go of a goal of including and acknowledging those things that can be controlled within an environment and measured within an environment, and acknowledging those things which can't be completely controlled, but which everyone needs to be overt about, as having important inputs into the outcomes that we're interested in.

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

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

The other concept which really dawned on me, and I'm not a physician by training, but I'm surrounded by physicians as well as yourselves, is do we include -- there was a lot of element of practice of medicine in many of the vignettes. You know, what to do when, when a scan needs to be done, who the scan is done by, things like that.

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

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

So how do you measure that aspect of it, because again, for someone who's very educated and is familiar with the health care system, their -- what good looks like for them is very different than potentially what good looks like for somebody who basically doesn't even have any expectations. They just want to feel better or they have an issue.

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

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

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

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

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

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

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

CO-CHAIR KOTAGAL: You're suggesting that some of our measures could be difficult in part, because of the balance.

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

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

But as I listen, I'm often listening to, you know, varications sometimes in asking the question. Is our problem really that this person is more person-centered and came late, or is our problem that 80 percent of the people are sitting in waiting rooms, because physicians don't arrive to the clinic at nine o'clock when the first patient arrives.

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

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

CO-CHAIR KOTAGAL: Point maybe.

MEMBER FORREST: Two comments. One is that I like the core concepts, and I thought the commentaries were terrific, and what had occurred to me is that this is ripping a little off from what Bruce said, but these core concepts set up dimensions for measurement, and what we're really talking about is a dimensional approach to measuring person- and family-centered health care, which suggests that (a), there's going to be a spectrum from low to high across each of these dimensions.

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

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

When we think about collaborative arrangements, what is important to understand at the microsystem is really issues around communication and empathy. As you go out to the higher levels of the system, you start talking about infrastructures that support collaboration.

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

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

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

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

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

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

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

MS. PACE: Right, and I think that -

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

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

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

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

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

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

I think that's a real challenge for

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

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

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

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

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

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

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

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

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

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

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

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

You know, think about the constructs

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

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

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

CO-CHAIR KOTAGAL: Do you want to --

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

CO-CHAIR KOTAGAL: Did I miss somebody here?

MEMBER deBRONKART: Yeah, Laurie and Ethan actually.

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

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

And it seems, as I read these, the heart of patient-centered care is really care individualization, and which brings me to something you said, Uma, about the extremes. I think we heard some really good examples of care being highly individualized, with the dilemmas it caused for people like Bruce, and not individualized at all, you know, in the palliative care world.

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

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

Uma, your story of really wonderful coordination, maintaining the patient-centeredness of that young man's care. But it's distinctive, and it's no surprise that there's a whole other panel addressing it. I think we can stay out of that sinkhole, of trying to make our definition include coordination.

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

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

So that's it.

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

MEMBER RADWIN: Yeah, yeah.

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

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

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

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

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

MEMBER BASCH: Thank you, briefly. I really liked the anecdotes. They were so interesting and they really -- as a provider and we all, of course, were patients in various contexts, they really resonate. I agree with the comment that there was a lot of overlap within the anecdotes.

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

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

Listening to patients, communicating to patients, flexibility of care to the patient context, and finally respect for the patient. So the listening -- so as I think about each of these, and I think you can collapse these pretty nicely into those, for each of them they each pose a very unique measurement challenge, because some of tem are more amenable to process measures, others to outcome measures.

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

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

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

(Off mic comment.)

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

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

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

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

MEMBER BASCH: Yeah, I'm sorry.

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

MEMBER BASCH: It's so hard to --

MS. PACE: I know, I know.

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

(Simultaneous speaking.)

MS. PACE: Okay.

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

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

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

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

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

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

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

But when they come together, it's for the person to realize better health outcomes that they wish to achieve, mediated by better health care. So at the center of this interaction is this idea, you can call it different terms, but it's co-decision-making, it's co-design my care plan, it's co-production of my health care regimen. IT's me working with, this co working with, in order to achieve best outcomes that I strive for.

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

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

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

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

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

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

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

MEMBER BASCH: But I think one of

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

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

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

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

So what I've been trying to do, I

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

FEMALE PARTICIPANT: Right.

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

Not only are the things all dangling connected to each other, but they've got springs on them of varying strengths. So you have a measure to make sure that Item 147(b) is in this circle. Well, you pull it and everything else moves, right. This is a major, major challenge, especially if we have burdensome ways that clinicians have to spend time documenting that they moved 147(b) into this circle, and the whole thing just doesn't work well.

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

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

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

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

The gyroscopes are what guided missiles, you know, and we need to -- if the measures we're working on aren't budging things, then we need to call out, with sirens and red flags, hey, everyone who's telling us to do measures, there's something else going on here, and work needs to be done to identify what those forces are, or all this is not going to make any difference, all right.

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

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

So they -- one last thing, a potent vignette on the quality. So to get back to the direct question, in the definition, I just think that it would make sense to put something in, either at the beginning or at the end, that when patient- and family-centered care is happening or is present, all right, the patient and family feel cared for.

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

MS. PACE: Okay, Joyce.

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

Because I'm going to just provide more ideas. I think what we are trying to do is to describe what a patient wants, and I am prepared for the battles we will have later on, with respect to what the measures will look like.

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

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

So I'm just thinking here about the outcomes that we want to see, and then we're going to have the problem of splitters and lumpers, because I think it was again Ethan who -- but you were talking about more operationalizing, so I'm going to forgive you on that one. I'm an Ethan groupie, so he can do no harm.

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

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

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

When it says that my care partners

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

FEMALE PARTICIPANT: Well, I'm sorry.

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

MALE PARTICIPANT: That's good, good.

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

I'm going to skip two and six for a minute. I'll come back to them, because I lump them together. The most important one obviously is the dignity and the compassion. The one about four, where I collaborate in decisions about my care to the extent I desire, or am able to choose the care partner -- oh, this is the one I want to skip.

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

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

I think number six, I would simply say my care partners provide any information I need in a format I prefer, period. I think everything else you've provided reflects an illustration of that. And again, this opens up the recognition that we have to tailor communications to individuals.

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

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

I want care that is coordinated. That is a goal that I have as a patient. So I want to see that as an end goal, and I think you should -- any clinician should be able to or should be striving to figure out how to coordinate the care that people need and people will need different types of coordination, depending on the circumstances, depending on the setting, etcetera.

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

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

People make choices about the system or the plan, but they are making choices that reflect a design. To say that I should be able to get it any way I want ignores the realities of issues around affordability, and the way we pay for services.

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

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

Finally in the first one, and I did comment on this, I think we have to have something about my provider knowing me with respect to my spiritual, social life. So there were a lot of comments on that. My financial circumstances.

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

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

MS. PACE: Okay, thank you. Jennifer.

MEMBER EAMES HUFF: So I've

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

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

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

I think culture. There are ways that you could get at that in measurement, but there are ways that you can't. So what is it that we can within the realm of performance measurement. So that's my introductory. So I was, like I said, inspired by the vignettes, so I'm going to add my own, that sort of illustrate some of my comments on the core concepts.

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

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

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

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

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

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

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

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

But I felt like my birth center and being there, my care team was my family, you know. There's a difference. I wasn't just a partner; I was a family, and I was in my home, you know, when it came to that. At the other place, I felt like a guest and a visitor, you know. It was a really different atmosphere. So you get some of the niceness.

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

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

This hospital is known as the baby mill. So four midwives to actually treat a very large metropolitan area. So two were busy, one was going on vacation, so I didn't get a midwife. I stuck with my OB/GYN, which was different from the first one, and I had a nice relationship with her, and I did feel like she would really respect my wishes and she did a lot of things.

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

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

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

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

Four and seven. So in that instance, the outcomes were really important to me and knowing that information. I learned that I wrote a lot on my previous experience, of my education that I got from my first birth. I didn't need as much as my second birth.

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

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

I have concerns about the cost being just related to the care partners providing the information, because that was something if you're an insured patient, really the role of the health plan, and I don't know if we're looking at health plans as care partners in this context.

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

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

I don't think there was anything in here that would have gotten at that being sort of the right care, that she wanted to get all the breaks. So again, I think that reflects going back to the patients. I think it's different than some of the other events, you know.

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

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

So how we can massage it, and also simplifying it. I'm struck by we've had the concept of right care, right time, right price. Very simple, you know what it is, and it is reflected in a lot of these things, but with a lot less words. So there may be a way to incorporate that concept, and build on a few things around the whole person, whether or not you sort of consider that right care.

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

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

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

You know, one might say okay, you

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

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

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

Was it actually our preference to

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

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

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

MEMBER EAMES HUFF: Yeah. So I'm going to say even though I ultimately got better outcomes with going to the academic health center, I think that was built on what was done with the birth center. So the birth center -- I changed my eating habits, because they sat down and talked with me, and went through that. I would not have done that with my doctor.

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

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

So people will tell me, forget about the care; you have the healthy basis, and yeah, it is important.

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

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

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

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

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

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

MEMBER deBRONKART: Oh we are? Okay.

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

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

But I wanted to say one thing about number eight, the care coordination and the communication thing, which is I think somewhere in here there has to be who is responsible for communicating with me. Who is ultimately responsible for primary communication with me, and like everyone else, I'll do a quick example.

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

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

There needs to be someone who's --

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

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

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

I would just be cautious about using those kinds of measures, having just filled out an HCAHPS myself, with the surgery, you know, with some surgery I had a couple of years ago.

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

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

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

I just finally go back to Dave's point, that we've been trying to do this for how long now, you know, and maybe we have to be a little more prescriptive, and maybe we have to be a little bit more concrete, you know, and what we're saying has to happen in order for that change to occur.

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

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

The other thing that Gene pointed out was even though he was addressing number one in terms of the core concepts, he also nicely described "I received the care, no more, no less, when, where and how I prefer," and actually I'd like to receive my health care in that center you described to us, but I'd like a health coach.

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

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

The other point I wanted to make was related to fear of partnering with care partners. There's a great fear within the medical community, and I have heard this many times. "Well, you know, the families, the patients, they're going to take over, and we won't be able to carry out the care we need to deliver."

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

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

The other point that was made related to the emails and difficulties with those, patients choosing multiple care partners. There are systems ways, in some respects, you can get around this, by having family meetings structured so they occur sooner. You have the right people in the room. The family understands the purpose of the family meeting and their role in that meeting. So just some other suggestions there.

The other thing I'd like to point out is what we're seeing families are the stewards of patient safety. How many of you have been with a family member or a loved one or a friend, when you have actually prevented a medical error? I know I have. Okay. I see many heads acknowledging that point.

So when we think about partnerships and including the family, I think that's just an important point to consider. I loved the point, I think Dave you made, about the clinician tweeting patients when he or she was going to be delayed. I think all of this work calls for the opportunity to innovate and innovate well.

MEMBER deBRONKART: It's not very expensive.

MEMBER CONNOR: Hmm?

MEMBER deBRONKART: It's not very expensive.

MEMBER CONNOR: Right, right. And then thinking about the 30 year-old patient, whose family didn't want to adhere to the diet that was prescribed for him.

You know, when we think about team-based care, and I think there have been some fine examples of that, one opportunity would have been to meet with the nutritionist sooner, if we're thinking about team-based care, and really think about using a strength-based approach with this family, so they feel that their knowledge is being acknowledged, and that they can control the situation from that perspective.

My last comment relates to the core concepts. My first inclination was why are they so long, why are they so wordy, and then I did back off a bit. I thought well, maybe we need this level of precision, since we are going to ultimately come up with measures for person- and family-centered care.

But it reminds me of the work done by the Institute for Patient and Family-Centered Care that initially started off with a much longer list, and then distilled that into the four core concepts that I think most of you are aware of, and you can even distill those four concepts into four words: collaboration, participation, information-sharing and respect and dignity. That's something that most people are able to remember.

My very last comment is the last point about communication with and among my care partners. I think transitions of care is a huge, huge problem in health care, and I sort of liked seeing that this included "among my care partners," because if they're not communicating effectively, and there are enormous problems with this, there is no way that a clinician can communicate effectively with a patient and family. So another issue to point out. Thank you.

MS. PACE: Okay, Sally.

CO-CHAIR OKUN: Okay, thank you. I realize I'm between now you and lunch, and Dave's commitment.

So there's so much has been said already, but I also want to acknowledge just how powerful the vignettes were, and how I am continually impressed by just how powerful any story related to anything related to health, in any way at all, is always powerful, and helps to move and innovate us in ways that we need to challenge ourselves. I think that's just one really important piece to always remember.

I'm not going to go into each of the things where I might have a comment. I'm going to talk broadly, and what I see missing here, although I think there's a lot of really good stuff, is sort of a lack of attention to the preparedness that we need to give to individual people to become patients.

So I think what we've done is we've defined what patient and family -- person- and family-centered care could look like when you're a patient. But I think what we've done is sort of taken people off the hook from being somewhat prepared, to engage in being a patient.

So I'd like to sort of challenge us to think about that. I do think there are ways to do that, and I certainly take that into consideration. Some people will be too vulnerable for that, but yet some members of the team need to then step up and say well, they are too vulnerable in this situation. So we need to start thinking about how we can be their champion for what they might need.

So I'm sort of always impressed by something I did about 10 or 12 years ago in a community-based project we worked on, and we came away with the ultimate statement. As we tried to integrate this type of care across one county in Massachusetts, and it was that living well, whether I'm well, ill, care-giving, whether I'm experiencing complicated aging, requires creative collaboration across all the communities that touch me, that all the communities that touch my life are going to have to have some role in my ability to life as well as possible.

Now I'm the only person who knows what all of those communities are on some level, right? So I think what we're lacking here is some way of being able to have an internalized mechanism for gathering that information in a systematic way, from real people about what their real lives are about, and then being able to integrate that into the patient's person- and family-centered notion of what care can look like.

So the other thing, as you know, I

come from PatientsLikeMe, and we have over 250,000 patients today sharing and learning from each other, and that's a network that actually is just another community, and we have to think about how we're integrating these novel environments.

But one statement that we use that I think is really important and just is really powerful, and can help us begin to think about how do we help people, individuals, begin to understand that they may at some point need to encounter the health care system.

It could be that that happens over time chronically, or it could be that it happens rapidly in a bike accident. There are different ways that you encounter it.

But at any point in time, I think if we ask ourselves this question honestly, even if it we ask it of ourselves today, given my status, so that means how am I doing today? Am I well? Do I live with a chronic illness? Is there something I need to be considering?

What's the best outcome I can hope to achieve?

So hope means I'm not asking for the moon. I'm asking for what's possible within the confines of what we've got available, and how am I going to get there. That's the fundamental question we have built PatientsLikeMe upon.

It's sort of saying as a person who knows what my assets and strengths and gaps and vulnerabilities are, what can I hope to achieve based on how I'm doing today, and how the heck am I going to get there, and who's going to help me do that?

So I think what's what I think is just missing somewhat fundamentally from what we've done. I think frankly it's interesting to me, because I think what we've done is we've taken person and family-centered care and made the concepts a bit provider-centric, because they're all about what you're going to be doing for me, and actually I think what we need to do is flip it slightly and say whoa, you know, I need to do something too.

FEMALE PARTICIPANT: Can we take a break?

MS. PACE: Yes. I think it's time for our break and lunch, and so we will reconvene at 1:15. So we'll, you know, if you want to, bring your lunch and drinks to the table. But I'll give you a little bit of a break. Than you all. Very good discussion, very provocative. Thank you.

(Whereupon, the above-entitled matter went off the record at 12:47 p.m. and resumed at 1:15 p.m.)

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

1:15 p.m.

MS. PACE: Why don't we all meander back to our places? We wanted to -- I know Mitra's been communicating with you all about the potential for getting together for dinner tonight, and so we've made some -- we have a place. Just to explain how our reimbursement system work, is that we cannot like pick up the tab for dinner.

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.

So we had to find a restaurant that is willing to give everyone an individual check, and so there's one that we often use, that people seem to like and it's close by to your hotel. So Mitra, you want to mention it?

MEMBER GHAZINOUR: Yes. So the restaurant is called Mayo Restaurant, and I can print the direction to the restaurant for you. It's for 6:30 p.m. tonight, and the reservation is for 20 people, and I think we have 16 or 17. So we have three additional spaces, if anybody would like to join the group.

(Off mic comment.)

MEMBER GHAZINOUR: Yes, I can take your name.

MS. PACE: But you're saying we have a big enough -- we have enough space for the entire committee to go, if they chose to.

(Off mic comment.)

MEMBER GHAZINOUR: Yes, yes. Her group is included. Sure, okay.

MS. PACE: Okay. So Mitra will print that out. We'll meet there at 6:30 or before, if you get there earlier, and look forward to continuing our discussions, I'm sure. Do you need -- you don't really need names or additional information?

MEMBER GHAZINOUR: No.

Public Comment

MS. PACE: Okay, all right. So this is the time that we set aside, to see if there were any public comments from anyone here in the room or on the webinar, and I know we just have a small audience contingent. But I will ask the operator, do you want to see if anyone on the phone would like to make a comment?

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

(No response.)

OPERATOR: At this time, there are no public comments on the phone line.

MS. PACE: And Kaitlynn, what about on the webinar? Any chat?

KAITLYNN: No.

MS. PACE: Okay, and anyone here in the room?

(No response.)

Definition and Core Concepts

MS. PACE: All right, okay. Well, we will pick up the next agenda item then, which is actually to spend just a few more minutes to tie up our -- finish or continue our discussion about the definition and core concepts. Let me just explain a little bit about what we're going to do the rest of the afternoon, just to put this in context.

So we wanted to, because we knew that we had to break for lunch at a reasonable lunch time, but probably if people still a few more comments to make about the definition and core concepts. So we want to finish that up, and then I'm going to spend a little bit of time talking about measurement framework, to prepare us for the afternoon small group discussion.

Before we go into small group discussion, we're going to have a couple of presentations by webinar and conference call on just some innovative ideas that are happening, just to again stimulate some thinking before we go into our small groups.

We will then go into small groups, where -- and we have given you an assignment. Hopefully it's okay with everyone, but it's in your packet, and there's a sheet that looks like this, and there's some instructions.

But I will go over those with you when I talk about the measurement framework, just to give you -- and there will be a staff person in each group, and you'll have one of your own committee members that will be your facilitator. But we will go over that again.

Then we'll see how we're doing on time. We may not come back to report out at the end of the day, if we need that time in your small groups, and may defer that to tomorrow morning.

So we intentionally had worked out several plans, to see how it was going and where we needed the time. So we'll cross that bridge when we get to it, but for now, why don't we see if there are any further comments, and I'd like to take this maybe until 1:30, and then we'll resume, and then I'll jump in with the measure framework.

But if there any additional comments, questions, suggestions regarding the definition and core concepts?

CO-CHAIR OKUN: I just would like to bring our attention to the line here, because I think this is important, before we go into the small groups.

For anybody who identifies something that they feel strongly about, they feel like that you know it would prevent them from moving forward for some reason, anything on the information or the definitions or the core concepts, it would be helpful, I think, for us to just talk about those somewhat now, and then as we go into the small groups, we all have some awareness of people's perspectives on that. So just throwing that out.

MS. PACE: I'll just also just one other thing. I'll acknowledge we have heard your suggestions, and you know, we can -- we'll continue to kind of mull those over. But I think as Sally mentioned, before we go into the groups, we want to find out if there are any strong objections to anything that we have to take into account.

But we'll continue to be working through these, as we continue our work.

MEMBER LARSEN: You know, one thing that I heard us talk about, that I don't necessarily see in here is that I think I heard that person- and family-centered care is a system attribute, not just an individual personal attribute.

I don't know if that rises to the level of one of these attributes or our definition, but you know, in many of the conversations I've had with people around, there's this tension between our measurement that's always focused on a person, an individual clinician, versus how we're thinking that it's very difficult for any one clinician to make this happen as an island.

MEMBER MAKAR: I have a comment. One of my questions is in regards to how this is ordered, because I feel that the coordinated care and transitions of care is really huge, and I didn't know if these were ordered. So I would ask the group to think about, you know priority order of them, if there is one.

Then the other issue was with number five. I understand the rationale to say "care partners," but I just think number five could be confusing with care partners and other care partners. Then lastly, it's about information being thorough and comprehensive, and not omitting key pieces.

So I guess what that gets to is very often, and we're trying to operationalize something in an antiquated system. But we're trying to apply this to what we have today, and also be future-thinking. I think what happens is you tend to think of your own space, because it's overwhelming to think of the continuum, and there has to kind of be a way to tie that in.

So the example that Jennifer was giving about the fact that she felt her midwife was really patient-centered. It just struck me that if they truly were, they would have been thinking about the high risk patients that then had to go to the AMC, academic medical center.

But that was a portion that they really weren't thinking about, because she was kind of on her own to deal with that. So it's a concept I just want to throw out there.

MS. PACE: And I think just I'd like to hear other comments about the care coordination. The way that last core concept is currently framed, it's really about the communication, and we know, you know, we've had some discussion earlier about care coordination being a very big topic on its own, and I know we've had another project on that.

So I guess, you know, I'd like to hear whether -- how you guys view that, whether care coordination is under person- and family-centered care, if it's another domain and, you know, obviously they're related. So that may be something to have a little discussion about.

MEMBER FIESINGER: Okay. I'll give you a quick comment on that, and then say what I was going to say. So coordination is very important. What I think is as a provider, if we're already -- coordination is dealt with elsewhere. That's fine with me. This could focus on communication, so get it coordination.

Meaning I struggle to get notes back from consultants, far maybe 90 percent of the time. So patients assume we all talk. So they assume I'm already doing it. The dirty reality is that I'm not. I think if we measured and pushed communication, a fair amount of coordination will follow. Not enough.

Then my comment I was going to make before is just I know we're not doing measures, but as much as our concepts can focus on creating things that are actionable, that I and the patient can see, because certainly what frustrated physicians, when I'm talking to physicians, trying to motivate them, is if they put forth a lot of effort and can't see any change, their first reaction is what's the point, and then you're frustrated and then enthusiasm drops.

So I think that's true for support staff, and I'd love to get granular and go to the nitty-gritty. But when I'm thinking about me in the room, trying to do something, something that's lumped together helps, and if it's something simple as "Was this visit good for you?" Okay, it wasn't. Can you tell me why? What's one thing you would have us change. Okay, great.

Because I did that with our residents. One resident said lectures are an hour. I'd like to have 30 minutes, so I can keep up on my charts. Great, because I'd rather not talk to you an hour. I can tell you're doing your charts when I talk to you. That was very helpful, and we can take action on it.

MEMBER RADWIN: I may be repeating myself here, but you can't have good patient-centered care without coordination. But the interventions to improve coordination are different than the interventions to improve patient-centeredness.

You know, I'm currently hoping to be testing on a model that looks at patient-centered care before transition and its related outcomes, patient-centered care after transition and its related outcomes, and the coordination activities that affected the amelioration or degradation of patient-centered care in that second setting.

And you really can distinctively measure coordination activities that are different, but influence patient-centered care. So communications is quite a bit different in some ways than coordination, in terms of how it's operationalized.

MS. PACE: Jennifer.

MEMBER WOLFF: So I guess I have a question, which has to do with how important it is to sort of tease out individual core concepts, and sort of split them individually, versus recognize that there is some overlap across these, and attempt to come up with core concepts that are more parsimonious, and I guess I'm wondering if you, Karen or others at NQF, could give us some direction, so that we can reflect on what our goal is in the afternoon activities?

Then the other comment that I had is going back to some comments that Sally has made a couple of different times, about the patient being part of the care team, and potentially this notion of preparedness as being something that may not be present in these concepts that have been numbered.

MS. PACE: Right. So I'll take part of that, and then Sally may want to add to it, and I think Gene mentioned this as well. In the second bullet point of number six about confidence and capacity to care for myself. I don't know if that encompasses, Sally, what you were talking about, of preparing to be a patient or participant.

CO-CHAIR OKUN: You know, it somewhat is, but it's even more fundamental than that. It's really sort of -- you know, I'm not exactly sure how to state it without actually having something that I will assume some responsibilities to the degree I am able to be a full participant in patient and family -- person- and family-centered care.

So maybe it's just another concept that needs to be in there, because I think once that's there, then the other pieces of it sort of fit with where my responsibilities might be. So I don't know if that seems to answer -- I felt that it was missing it, and that it really was leaning more on what's other people going to do to make my care better, when in fact I need to come to the table too.

We know that there are going to be some limitations for some people on that. But we as a team need to figure out what that is. So it feels to me like it's still one more statement, and I'm not sure if it -- and then with that one statement, maybe there's other way we can look at some of these others as being redundant.

MS. PACE: So and then to answer your question about the other suggestions we heard, I think, you know, we're obviously going to take those all into consideration. The charge for the afternoon will not be to continue working on the core concepts, but to start thinking about measure concepts.

So I think it will be an iterative process, that as you get into that, it will also maybe change our thinking a little bit about the core concepts. But we huddled about that a little bit about the core concepts. But we huddled about that a little bit. Should we really, you know, as a big committee continue to work on, you know, changing the words, etcetera, and we think that maybe still going into the exercise to work on measure concepts, will also help us sharpen maybe how we want to view the core concepts.

So we kind of see this as an iterative process. So your comments are not being lost. They're all being recorded, and we will definitely take this all into consideration, and maybe that's something that we'll be able to come back to tomorrow.

But we want to keep moving, but certainly when you're in your small groups, you'll be thinking about those things, and certainly we can continue to think about how we want to hone those core concepts to be the sharpest they can be, and as parsimonious as they can be.

MEMBER LEFF: I just want to build on Sally's comments about this notion of preparedness or responsibility. I think that really is a very important concept to try and bake into this for a few reasons. Number one, I think that if, you know, at some level measures like gets developed, a measure set needs to be sold in some way to users; otherwise, it's dead.

I think that in terms of making this more acceptable to the provider world, providers who hear that patients actually have some skin in the game, and have to actually bring something to the table, I think that actually helps quite a bit in moving the construct forward. So just put something in for that.

MEMBER DUBOW: I actually wanted to ask Kevin a question about his observation, but I have to demur here. I worry a lot about the skin in the game term, which forgive me, I hate, and I think we have to be very careful about the patient responsibility, the way it's framed. There are patients for a whole host of reasons who have no capacity to be engaged, and I think it's the responsibility of a clinician to dance with the one you brung to the dance.

It's just -- it's some patients are easy to deal with, some are not. But saying that oh, the patient was impossible is an out that I just don't think should be allowed. I have grave -- I know that's not what you're saying, and I know and I agree that we need to equip people with the information and the confidence and the tools to manage their care when it's feasible.

But I think we have to be real about the fact that there are people who are going to need, you know, just major effort to push, you know, because there is a patient who just doesn't get it, who doesn't have the capacity, who has no caregiver to support.

I just think we have to recognize that again, it's not so easy, and when we can do it, great. But I think we need to be careful with our language, because it becomes a political weapon, and I don't think we want to go in that direction. But Kevin, I wanted to ask you about your observation about systems.

Again, my very narrow focus here is that if we identify the concepts, then the measurement that we think about can deal with issues around attribution and all of the rest. So that as long as the various settings of various providers are, you know, have some responsibility for the outcome of that particular part of the core concept, then doesn't it get taken care of in the measurement area?

MEMBER LARSEN: I think so, but I'll just say from years of developing quality measures, that they're currently highly tuned to our fee for service system, at least the ones that I'm thinking about in the federal space, and that has its own set of constraints, that all of the sudden quickly narrow the measures into the purpose of federal payment program, fee for service models.

So insomuch as there is an opportunity to measure, tightly aligned to a PQRS fee for service system, great. Sometimes what we find is the outcome attribute we really care about is very difficult to measure at one doctor, through their fee for service claims model.

I'm just asking us to be sure that we've articulated -- sometimes if it's an individual behavior question, if it's a microsystem question, if it's a miso or macro system question, I think we're likely going to be best served by some discussion across to those things, so that when we're out of here, we have a more sophisticated sense than this is just an individual person's behavior issue, or that there's the only lever we have, is that a public health large-scale system.

I think we've got levers along the spectrum, and we're going to have to be thoughtful enough that our outcomes will span those.

MEMBER DUBOW: Well, it's a question of identifying the expectations and expecting whichever level of the system, whether it's at the individual level, a team or a larger system, has to take accountability and responsibility for recognizing and honoring that behavior.

So you know, I mean I just think that there is room to think about using the measurement space to think about attribution, and to think about levels of accountability, without being saddled with messing up our core concepts.

MEMBER LARSEN: Yeah, agreed, and I

just -- just to be fair, I kind of come from a systems engineering standpoint. So one of my favorite quick little stories, if any of you have read the Virginia Mason transforming health care using Lean, patient-centered model using Lean, the point that they talk about there is bringing some Japanese Lean experts over to their health system that they're really proud of, and say look at how fantastic, you know, we're doing at this.

These Japanese Lean experts say well, what are all these rooms with all these chairs, and they say well those are waiting rooms. They say wait happens in waiting rooms? Well, they said patients wait, and the Japanese said doesn't it embarrass you, that you have people wait.

The people at Virginia Mason said well of course people wait. That's what we have waiting rooms for, and the Japanese people said but isn't their time valuable? Isn't all of this about making sure that you're really efficient and tuned to them?

So there's not one single actor like in that, and unless you open up the measurement space to that sort of systems level measurement, like what if a measure was how much square footage you have dedicated to waiting rooms, and the ultimate goal is zero, you would never -- you'd never like focus the right kind of work at that problem.

MEMBER WALLING: Well, I just had a question about number four, and the use of care partner. I wanted to make sure that this included in a care planning for future, when you may not be able to make your own decisions, to preserve autonomy, even after you lose your decision-making capacity.

So I choose the care partner. I wasn't sure if that meant a family care partner or a friend care partner, or a provider care partner.

MS. PACE: Sally, do you want to talk about care partners, because I know we --

CO-CHAIR OKUN: Yeah. I was kind of surprised that we didn't get any -- a lot of reaction to it frankly. But you know, in the interests when we were having one of our chair meetings, and we were struggling over the providers and clinicians and the words and then family, and so finally it's becoming more and more used in circles that I've been at lately, with this concept of where it's a partnership.

So I said well, maybe we should just be calling ourselves care partners, you know, and yet that's a new term, it's a new way of thinking and I'm not sure, you know. If we're going to use things like that, we need to define them, and we need to be more clear about them.

So I was actually waiting for some reaction and didn't get some. So I guess it's time for us to decide that sort of thing. So I think in this statement it was meant that whom I choose will be the one who's making my decisions. That presumes that I may have done some advance thinking about who that might be, if I can't do it for myself. But that gets back to the preparedness question.

So my influence is on that particular statement. I didn't explain that influence by saying well that presumes that someone's actually made some active step to name someone.

In the absence of that, however, I would also suggest that as teams, and if we're well-functioning teams, that we also have also identified who amongst us on the team might be the best to take the responsibility to sort out how can we best be sure that decisions get made, in the way that we believe this person's decision-making would drive, if they could do it themselves.

So it doesn't necessarily need to be a family member. It could be if I'm able to designate that person, and I'm prepared enough to think about putting that in place ahead of time, great. If I haven't, to the degree I'm able, I'm asked about that, and when I'm not able, somehow or another this person and family-centered environment considers that my incapacity leaves me unable to make that decision, and defines within the team how best to do that, either through the structure of the organization I happen to be in, by virtue of where I'm getting my care and how that gets determined that way.

So I think there's a bit of openness left in here, and some interpretation needing to be thought through, in terms of where the measures might fall out. But the intentional of care partners was an inclusive term, family as well as other people who matter to us, as well as the people who are providing our clinical care.

MEMBER MACDONALD: Having not been involved in the original draft of this, what was the reason for not saying family, and then defining family as CMS does, where patients have a right to choose whoever they want to be their quote-unquote family?

MS. PACE: Actually, it does say this in the definition, their defined family. So basically, the idea is that the patient defines who their family is, and then --

MEMBER MACDONALD: And so with that in mind, why wouldn't we use the same terminology throughout the documents? I think this is going to be very confusing, having one regulatory agency use family and defines it as it is defined earlier on. I guess I was speaking to the definition you're using under core concepts confusing.

MS. PACE: So your suggestion is that we should use family, and what term would you like to use for everyone else? Do you like care partners?

MEMBER MACDONALD: Well, the patient defines who family is.

MS. PACE: Exactly.

MEMBER MACDONALD: So I would just

put that in there. I mean I'm simplify it.

MS. PACE: But how would you -- you don't, you're not going to consider clinicians part of the family?

MEMBER MACDONALD: No, no.

MS. PACE: So then the question is what term do you want to use for --

(Off mic comment.)

MEMBER RADWIN: In all the anecdotes we heard, what role is not included in clinician?

CO-CHAIR OKUN: I would suggest as most of us think about the word "clinician," we wouldn't necessarily think about the health coach that Gene had described. That would be my impression. It wouldn't necessarily be my opinion, but I think that that person might not be someone seen as a clinician.

MEMBER RADWIN: How about "clinical team" then?

(Off mic comment.)

MEMBER LATTS: Is somebody not using

their microphone?

MS. PACE: Sorry about that. I was saying that part of the thinking of using care partners was to really emphasize what we say in the definition about collaborative partnerships. So but certainly, you know, I think the point about family is well-taken. We can just refer to family in the appropriate places.

But again, we can say providers. The other term that we had been using was providers of care, which could encompass clinicians and everyone else involved.

MEMBER deBRONKART: So I'll acknowledge that I've just walked in on this, so I hope I'm not redundant. It seems to me that the context for the whole relationship is essential, and is actually more important or at least as important as how we identify people within that context.

What I see and hear about so often is -- and I know many people have said this, but I think it's our job to hammer on it, the absence of a team culture and team-oriented behaviors, just the fact that you can have six different people, six different doctors, and I know the culture is I'm in my silo and I don't care about you.

Nobody would say that, but it's the reality, and so if we have the team culture, then you have people who basically work at the practice, right, and you have the family, the patient, the family, the caregivers, everybody who doesn't work at the practice, who comes to the practice for care, right.

And sure, we may need to come up with a term for the people who work at the practice, but I think the more important thing is the sense of a functioning team.

MS. PACE: Okay.

CO-CHAIR OKUN: Can I just add an anecdote to this, and that is part of this I will have to admit is influenced somewhat by another project that I've been involved in for some time now, and a few years ago, as part of the IOM workshop work group on team-based care, we created a document called core values and principles of team-based care.

One of the things that we worked on a lot was thinking about what are the roles and responsibilities. What are the core values that team members need to have, and one of the things we realized late into the game was that we really were talking solely about the professional or the clinical team members, and we actually left out what roles and responsibilities might family and patients have in this situation?

So actually a follow-on project from that, particularly that first paper, was now we are -- have convened a work group. We've been working now for just about a year on the patient's role as a member of the team, and thinking about what does it mean to be a member of the team.

For those people who may not want to

be a member of the team, we need to acknowledge that and understand that. But that by not suggesting that they're a member of the team sort of marginalizes them somewhere along the way. Again, puts them in the center, but isn't necessarily saying I'm in this with you.

So some of that's been influenced by that, and I think the definition where we state collaborative partnerships among individuals, defined family and providers of care was really where sort of this notion of care partners emerged from.

So that said, I just want to give a little context, because we are actually in conversations on a few different levels in a few different groups, and it's getting influenced and leakage starting to spill over to different ones.

MEMBER deBRONKART: Well and coming from an engineering background, and I also -- I mean as a student, I'm both a student and a victim of disruptive innovation.

My industry typesetting machines got disrupted all to hell by desktop publishing, and what I saw was you could look at an overall process map, except I mean in vague terms, not micro-details, of what happens over the course of time that was useful, that produced some value.

What we're seeing, and this goes directly to why Sally's point is so important, is that there is a shift in where certain activities get done, all right.

Now in the context of diabetes, I'm told that 100 -- I'm not expert on the disease. I'm told that 100 years ago, in order to know what your numbers were, you had to go to a doctor, right, and clearly knowing what your numbers are is useful. That no longer requires going to a doctor, and we won't understand how things are shifting and how we need to reach out on things, if we don't realize that.

So and because what's happening, like in Kevin's story, a whole bunch of things are actually done effectively in the home, which takes a load off the system, which in turn of course points to the other, the mega-elephant in the room, which is that there are a whole lot of people who don't want their income to drop, as more work gets done outside.

MS. PACE: Bruce.

MEMBER LEFF: So just a comment. We've been talking about "the team." I think one of the implications, or at least an inference that I've drawn is that I think much of the conversation is in a primary care context. Maybe not completely, but I think that's a reasonable inference to draw, and I think we've been talking about team as a monolithic thing, one patient, one team.

I'm reminded of some very excellent work that Hoangmai Pham published a few years back in Annals of Internal Medicine, which suggests that the average older -- average Medicare patient with multiple chronic conditions sees on average three different primary care physicians, which really screws things up at some level.

The other thing I would just throw out there is that -- and I do a lot of care in the realm of home-based primary care, where seasoned folks with multiple chronic conditions, functional impairment, cannot access the usual ambulatory care system. Lots of social overlay onto their medical conditions.

In truth, you really cannot manage that population effectively without probably somewhere in the neighborhood of 10 to 15 different types of services that need to impact on that patient, that go way beyond the medical, way beyond the medical.

So if you're actually thinking about person-centeredness to affect a set of outcomes for people who really need the most person-centered care, I think you have to think very broadly in terms of scope, of what that team looks like. But again, that creates various levels of complications, attribution, etcetera, etcetera.

MS. PRINS: Chris.

MEMBER FORREST: I think the core concepts are very reasonable, and they will be -- they lend themselves to creating operational measures, which is a very nice piece of this.

But they're possibly incomplete, if we really want to take into account the fact that patient- and family-centered care, person- and family centered care is not only an experience of a person, but it's also a system level attribute.

So when you say "my care partners value," that is an experience of person- and family-centered care. It is not the system attributes that enable providers within that system to affect that outcome. So we could think about this as a driver diagram, where the outcome is the experience of person and family-centered care.

It does matter if the patient or the individual experiences that. Then there are these eight primary drivers. These are things that have to happen on the ground, very close to the patient. But then the secondary drivers are the system-level attributes, the things that you can actually change from a policy perspective, that influence the primary drivers.

So that's missing from the core concepts. On the conceptual level, they're there, but the way these are written, they're only focused on the primary drivers. So I think we're missing a big opportunity for measurement.

MS. PACE: And that's what we'll get into with the measurement framework, exactly. So we'll --

MEMBER FORREST: But it also gets to

the wording. I mean yeah, the measurement framework's important, but it's how these are worded, and some recognition perhaps in the preamble that we recognize that this is the experiences of, but that there are system-level attributes that influence the capacity to achieve these.

MS. PACE: Okay, good.

MEMBER MACDONALD: I think that's what I meant by structural actually. I mean it's what's behind this outcome, and I think that is a very important point.

I just wanted to weigh in quickly on the care partners, that I do find it rather confusing. From a lay perspective, it's not a term that I'm familiar with, and if it means both clinicians and family, then I think it can be quite confusing.

Like in four, "I choose the care partner I prefer to collaborate in those decisions for me." I don't know if that's the family or the clinician. So it just would be good to separate it in some way.

MEMBER EAMES HUFF: I also am going to comment on the my care partners. I do like that it's broad to get sort of all-encompassing, but I would agree that having family in there is too broad and a separate concept. The thing that I think is missing from it is it seems very clinician-focused, and I think there are some other people involved in care that actually help with patients under care.

So I'm thinking of like receptionists, administrative staff, you know. It could be the person that is the cafeteria, things like that. Those touch points are really important and getting on them. I don't know if -- I don't think we're planning on doing measurement in all those areas, but I think sort of recognizing that there's non-clinical staff that are really important.

MEMBER JHINGRAN: So two comments. What I've been thinking about is how can you make the same core concepts for a very simplistic patient versus the more complicated patient, and an analogy which came to my mind is I'm sure everybody's familiar with the SF-36, which is a health status questionnaire.

You have a six-item version and then you have a 36-item version. So you could still have the same core concepts, but go deeper and more granular for the more complicated patients. So that's a thought that came to mind.

The other thought is, and again this could be going into measurement, but you could have the same core concept, but it's going to look different from the perspective of the patient versus the perspective of the clinician.

So you could have the clinician portion or a health care partner portion, and the patient portion, and then you can get even more sophisticated by looking at concordance between the two. Because the patient might say my physician did not communicate, whereas the physician might say I did.

So understanding what that concordance is, and understanding where the true gaps are and where the strengths are, where things are going well, could be ways to kind of get to issues which finally make a difference in the patient's care.

MS. PACE: Ellen.

MEMBER MAKAR: So regarding the care partners, I was thinking if you wanted to just say family care partners and then the other care partners, that might work, and then I agree. When we were talking about non-clinical folks, I think they need to be included.

But also I think administration, and that's more of a structural or a secondary driver, is including that level for acute care, but also across the span and in a way trying to put in the payors, because we are kind of missing that piece, and we know that a lot of that decision-making is driven that way. So just a way to think about that.

Lastly, we were also talking about what you were saying. So I think it might be a helpful exercise to look at these the other way, because these are very much the patient speaking, and it would be interesting for the care partner to say what would be person- and family-centered care. How would they deliver that?

CO-CHAIR OKUN: I was going to add one comment on that. The intention of the word "care partners" at the time that we played around with this was frankly to be inclusive of whomever's touching the patient.

So I know that that's way broad, but it was one attempt to be able to say, you know, one patient-one team concept, as Bruce mentioned, actually came up in an IOM meeting a couple of weeks ago from a patient, who said I just -- I'm one patient. I want one team.

I understand that that team may be

lots of you and you may not be connected, and you may be in different places, but you figure that out, and help my care seem like it's coming from one team.

So the idea of the care partners was really sort of that inclusive idea, that it could be -- it could someone in their book club who supports them on some level emotionally, and it's the only person they're able to talk to about where their anxieties are and stuff.

MEMBER NELSON: I fundamentally -- I think the idea of moving towards the term person not patient is a good idea, focusing on partners, not providers vis-a-vis caregivers or other supports is a good idea. It's a direction that we'd like to move to.

I'd like a friend who had a rare form of cancer in our neighborhood. He actually didn't come to our system. He went to Fred Hutchinson. He came back and he was bragging about the care team he had at the

Fred Hutchinson Cancer Center in Seattle, that he had a great team and he was the captain, in a very rare form of cancer.

Then he came back and has a primary care system and a cancer support system. So he's still alive and doing very well. But I think this idea of care team and me in the center goes from primary care to cancer care to well child care etcetera, and it's the correct direction to move towards.

It's an intriguing idea, to build on Chris' point and others have made the point, that it would be good to have a summative statement/future measure of overall person-centeredness, not patient-centered but person-centeredness, and in the -- in the IOM Chasm Committee discussions, now at least a decade ago, the overall sentiment around person-centered care was a paradox and controversial.

But I get everything I want and need exactly when I want and need it, and the paradox is what I want and what I need may be two different things. But we live with paradoxes. But I think it would be helpful if we could have an over-arching sentiment, that could relate to the overall macro system, you know, the whole system and not pin it on a particular Troy, my doctor Troy or my doctor Jeff or my doctor Annie, that it's really as we move into person and population health, we want to move our attribution out to the system that's providing personal and population health.

MS. PACE: Okay, Ann. One last comment and then we'll move onto the next session.

MEMBER WALLING: It's really brief. I just -- when I was reviewing the materials before the meeting, I found it actually very clear to read the summary of the principles that was on the agenda. So at the 10:30 a.m., when it just listed 1-2-3-4-5 --

MS. PACE: The short ones?

MEMBER WALLING: Yeah, the short was

easy for me to comprehend and kind of -- it's just a thought.

Measurement Framework

MS. PACE: Okay, all right. Well, we're going to switch gears a little bit. I'm going to do a brief overview, talking about the measurement framework, and this was in your materials and it's also in some information in your packet, and we'll stop at 2:20, because we have some people joining us by webinar, and then we can resume just prior to going into our breakout groups.

So next slide. So I'm going to again put this a little bit into context just so that you have these things in the back of your mind. But NQF does endorse performance measures that are based on an evaluation of the measure against a standard set of criteria, to ensure it is suitable for accountability applications, in addition to performance improvement.

So the measures that NQF endorses

are intended to be -- obviously, we want measures that will be useful for improvement, or to identify where we need to improve. But they're also intended to be used in public reporting, pay for performance, etcetera.

Next slide. So these are our basic, our major criteria. The first one includes evidence, performance gap and priority, and we refer to this as importance to measure and report. This is a must-pass criterion, and I'll talk a little bit more about that, because it's most relevant for measure concepts.

But I just want to -- the reason we put this first is if it's not really important to measure and report, then we really don't need to worry about whether it's reliable and valid. What would it be measuring? The next criterion is reliability and validity, which we refer to as scientific acceptability of the measure properties.

This is also a must-pass criterion,

and again, if it's not reliable and valid, then we have risk and misclassification and improper interpretation. Again, think of this in the context of being used not only for improvement, but for accountability.

Feasibility, because we want performance measurement to create as little burden as possible. However, that's not a deal-breaker and hopefully, you know, we can improve on feasibility over time if it's something really important to measure.

Usability and use, that we really do want to see a plan for the measure to be used in an accountability application. If it's not, then you know, NQF endorsement may not be necessary. Then we have a process of looking at related and competing measures, to try to minimize burden.

So just a little bit more about the importance to measure and report, and this will play out as we go through these slides. But our criterion is about the empirical evidence for a structure, process or an intermediate clinical outcome, and we have very specific guidelines about the quantity, quality and consistency of evidence, to support having a national standard performance measure on a structured process or intermediate clinical outcome.

With outcomes, we really want to see a rationale that outcome is influenced by at least one health care structure process, intervention or service. Remember that we consider PROs and experience with care as outcomes.

So we're not asking for systematic reviews of evidence of what influences an experience with care outcome. If it's important to patients and consumers then, you know, it's an important experience, as long as there is something that the health care system can do to influence that.

Performance gap, and this includes disparities across population subgroups. But we really, if we're going to invest in a national performance measure that requires data collection and reporting, we really want it on something that is not already a terribly high level of performance, because if everyone's doing it, then we probably don't need to invest in a whole system to be collecting and reporting on it.

High priority, and this I mentioned earlier for PROs. We really do want to see some information demonstrating that it's valued and meaningful to patients and consumers, and then there's a criterion about composite performance measures that we won't get into any detail today.

So just again, some clarification. Some of you did participate in the PRO and performance measure project that we had in 2012. But one of the things that we learned as we were going through that and talking to one another, is that we did need to clarify our language.

So I just wanted to mention this, you know. We really considered PRO, the patient-reported outcome, which you saw a definition earlier, as kind of the concept, and we have two examples here, one of depression and one with a person with intellectual or developmental disabilities.

The PROM is the instrument or a single item measure. So you know, the PHQ-9, in the case of the intellectual developmental disability, the single item measure might be do you have a job in the community.

Then the PRO-PM or the PRO-based performance is what -- when you actually have that patient-level data, and aggregate it out to be able to say, for example, what percentage of my patients with a diagnosis of depression actually had remission of their depression symptoms within six months or 12 months, or in the other case, the proportion of people with intellectual or developmental disabilities who have a job in the community.

So again, just to kind of get our minds around, because I think a lot of the things that we'll be talking about with person- and family-centered care might be experience measures and to think about the patient level measure versus a performance measure, where you aggregate that information.

So I also wanted to just talk a little bit more. Uma mentioned it this morning about the PRO-PMs and relation to person- and family-centered care. Certainly, a lot of the core concepts, and I think several of you mentioned this, really seem to be in the PRO domain of experience with care.

It is describing what the patient or family should experience, if they're, you know, receiving person- and family-centered care, or participating in person- and family-centered care.

So and that would be a patient-reported outcome, generally collected in a survey. We're familiar with CAHPS surveys, for example. PRO-PMs for other domains, such as health-related, quality of life, functional status, symptom and symptom burden, health-related behaviors are very important, but they may be more indicative or indicators for quality of care in the other domains. So effectiveness of care, safety, etcetera.

So this is where it gets a little dicey, because using a patient-reported outcome may be very important in delivering person-centered care, but aggregating the data for that outcome.

So for example, if you measure function and patients who are having a hip replacement surgery, and you want to have a performance measure of the percentage of patients with improved function after hip surgery, that may be very important for the patient.

So having discussed that with the patient and measuring that with the patient, an important part of person-centered care.

But if you're looking at the percentage of patients who had improved hip function, that may be more of an indicator of the clinical effectiveness. So again, we'll have to kind of sort through these things, but just kind of laying these things out for you to have in the back of your mind as we start into our exercise to look at measure concepts.

The other thing to keep in mind about using PRO measures or PROMs in practice, is that they may not even be indicative of providing person-centered care, if they really are just a data collection vehicle.

So you know, sending out a PRO instrument to a patient, but never discussing the results or using it in, you know, planning the care, monitoring progress would probably not be very person-centered. It's really a data collection process.

So again, there's all these potential interactions and things. You know, just because it's a PRO doesn't mean it's measuring person-centered care, and it doesn't mean that using it if it's just a data collection vehicle.

Okay, next slide. Okay. That's all right. Some other things to keep in mind when you're thinking about measure concepts is that again, you know, meaningful to consumers and built with consumers, focused on the entire experience rather than a single setting or program to the extent possible, and measured from the person's perspective and experience, when that's the best source of information.

Certainly when you're talking about a patient's experience, they're going to be the authoritative source.

Next slide. So just wanted to talk a little bit about, you know, I'm sure you're all familiar with the kind of classical structure process outcome assessment of quality, and in general, NQF has a hierarchical preference for measures of outcomes, and then intermediate outcomes and finally process and structures that are most closely linked to desired outcomes.

So again, as you're thinking about performance measures or measure concepts for performance measurement, to be thinking about this, in terms of what is the evidence that a structure or process is really going to affect that outcome or experience of patient-centered care.

The other thing that happens, and I know someone already mentioned about sometimes performance measures or processes end up being kind of a checkbox, and this is just to talk about that, you know again, if we're going to measure a process, we want something that's closely linked to the desired outcome.

So this just kind of illustrates that you may have, for example, that you're going to use patient-reported outcome instruments in delivering care, and you may have a structural -- the structure is that your organization has a policy and procedure to use these patient-reported data. They've identified a set of PROM standard data collection instruments that have been validated.

Then in the process realm, staff have to identify which PROM to use with the patient, ask the patient to complete the PROM, review -- actually review those results with the patient, and then use as a basis for planning care, monitoring progress.

So my point here is is that if we have a performance measure that says, you know, you use PROMs, it kind of gets in that realm of what people criticize, is that you know, you're just checking a box, and just by using the PROM, it's not going to ensure that you reach the outcome. You have to do all these other steps.

So it's kind of one of those things that it's necessary but maybe not sufficient. So you know, just measuring something that's very distal and that requires multiple steps before you actually achieve the outcome, may not be the most efficient place to put our resources for performance measurement.

Next slide. Okay. So if we're looking at the, you know, outcome, process and structure, again you know, right now the way the core concepts are worded and as several of you mentioned, these seem to be kind of in the realm of the patient's experience, what they will experience. So we would see that as an experience with care outcome.

There could be various processes that will help support reaching that particular outcome, and these would be the interactions between the health care system and the person and family, including interventions, treatments and services, and then there can be structural measures or organizational structures and system that support providing person- and family-centered care, and we already talked about some of those.

So this leads me to what we started in the draft about a measurement framework if we were using the structure process outcome aspect, and if you all have a copy of that in your folders here, and this is just the very first one.

This is just for illustration. This is not to suggest this is what we should be measuring. It's just to get you thinking when you get into our next exercise, in terms of starting to think about measure concepts.

We would probably encourage you to think about measuring the outcome directly or the experience directly, or other things that might be considered outcomes, and then you know, are there processes and structures. I think it's important to --

I think several of you already have mentioned that in this area, there are probably lots of different processes and structures that will support achieving those core concepts, and they may vary according to the patient context or service context or setting context.

So it may be very challenging to try to identify processes that rise to the level of, you know, this should be a national standard performance measure, meaning pretty much everyone should do it, and do it in a prescribed way.

So again, just to be thinking about when you start looking at potential measure concepts, some of, you know, how these things might be structured that support our processes, and where do we really want to focus performance measurement, especially from the standpoint that many of you had brought up about parsimony and simple.

I think that will be our challenging going into these groups, of how can we achieve this as simply as possible.

So as you start thinking about it, there's several again questions to keep in mind. Is there evidence for structures or processes that would indicate all specified entities should really implement in their systems of care and be the focused of an endorsed performance measure?

The next question, and I'll take a few minutes, is could information on some structures or processes be useful in a standard label, and I'll give you an illustration of that. Are there outcomes that could be measured besides the experiences represented in the core concepts?

And again, you know, where patient-reported outcome measures fall in measuring person- and family-centered care. So next slide, and then we'll go on to our next speakers.

So Kevin brought this idea up early on in some of our discussions, is could there be a nutrition label for person- and family-centered care? So I think kind of the essence of the nutrition label idea is you have a standard set of items. There's standard definitions that go with these. There are standard ways to present the information, and generally a standard format or layout.

So next slide. This is just, you know, the question. Are there certain things that would be useful to lay out in a standard way, that would be useful to patients and consumers, that would indicative of person- and family-centered care?

You know, I put some in here just to stimulate thinking, but you know, and these may or may not be the right ones or useful ones or maybe nothing. But it is something for us to think about as we go into our small groups, and of course the key thing is, you know, would it be useful to patients and consumers.

But a couple of things on here. For example, you know, communication options. Can people communicate by phone, email, text messaging? Do they have access to their medical record? Is there a connection between personal health record and their medical record? You know, are there patient and family support groups?

Maybe the first one is just do they have a patient and family advisory group? You know, so maybe think about, you know again, we've all had experiences as patients and patient advocates, to kind of think about, you know, if you had information at a glance, what would be useful?

These may not -- and also these may be things that aren't, don't lend themselves well to a typical performance measure. But you know, you can have things on here like a link to their quality performance measures or, you know, people have been talking about affordability and transparency of cost, a link to a price list.

So just think about, you know, what might be useful in terms of, you know, gauging person-centeredness or at least finding a provider that matches your preferences. Yes, go ahead.

MEMBER LARSEN: So the reason to bring this up, that part of my research life is in health literacy, and health literacy, I kind of started thinking about reading, that really evolved as a science around how do consumers of health care understand information and make decisions.

One of the things we studied in the health literacy world was the nutrition label, and the reason for that study was because they made some fundamental shifts in the labeling world, and those shifts didn't actually change the measurement exactly. They standardized information display, to help with better comparability.

So an example is serving size. So it used to be that the companies that produced food could decide whatever serving size they want, and then they would tell you how many calories and how much fat and whatever else was in it. What they did with nutrition, the new nutrition label was say we're always going to define serving size for liquids as eight ounces.

We're always going to decide serving size for carbohydrates as half a cup, and then you'll get calories in a sort of standardized fashion, against these sort of standardized serving sizes.

They also called out how to highlight -- to highlight particular information that people thought was sort of most relevant, and it seems to me as I was thinking about this work about person- and family-centered measurement, that part of our charge to making measures that matter and that mean something to consumers is not just in the content, but in the sort of form and format that we would recommend.

So this is to sort of call that out and say, you know, we have an opportunity here not just to talk about 15 or 30 individualized items. But is there sort of a system of measurement and engagement that actually gets to good meaning and decision-making on behalf of the people that we are hoping to work with?

MS. PACE: All right. So I think we're going to go ahead and move on to our speakers that are going to talk to us via webinar. So if we could bring up their slides, and let me just do a check. Is Dr. Holly online?

(No response.)

MS. PACE: So I believe he is. Operator, do we have James Holly, Larry Holly?

OPERATOR: He had just disconnected.

MS. PACE: Pardon me?

OPERATOR: He had just disconnected. He's dialing again.

MS. PACE: Okay, and what about Susan Yount?

DR. YOUNT: Yes, we're here.

Innovative Approaches

MS. PACE: Okay, Susan and Amy, okay. So we'll wait just a moment for Dr.

Holly to come back online. What I -- and just to again, as I said, we just asked for these presenters to give us some -- they have some innovative things to share with us, and again, it's just to stimulate thinking. It's not to say that we need to do this or but just again, in the spirit of our exploring these topics, and some of the things that might be possible. So is Dr. Holly on?

DR. HOLLY: Hi, I'm here. I was connecting and I hung up.

MS. PACE: Okay. I've done that myself. So Dr. Holly is with Southeast Texas Medical Associates, and he's going to talk with us about his approach to person-centered care, and specifically on a concept of convenience. So Dr. Holly, you'll just need to signal to us when you want us to advance the slide.

DR. HOLLY: Okay. You can advance it. Our practice is a multi-specialty group in southeast Texas. We are accredited by NCQA as a Tier 3 medical home, by Triple HC for our medical home and ambulatory care, by URAC and by Joint Commission. We have all four accreditations.

We are heavily involved in patient-centered care. We use CAHPS, HCAHPS and also Community Council, for making sure that we are focused on issues such as shared decision-making, activation, engagement and other subjective but critical issues related to medical home and patient-centered care.

The concept of convenience as a subsuite or placeholder for quality developed a few years ago. The key to all of what we do related is coordination. The statement on space seems a little bit for us a simplification. How can doing things the way patients want, when they want, where they want and how they want contribute to the achievement of quality outcomes?

Next slide, please. This was -- next slide please. Oh, did I move that. Can you do the next slide please? Am I not connected?

MS. PACE: You are, you are. Just let's go the next -- one slide. There you go.

DR. HOLLY: Okay, one slide. That's it. Coordination of care is the process an organization goes through to assure the patient receives the care they need, and coordinated care is the outcome, the experience and perception the patient has when the care has been organized for continuity, convenience and for compliance, and use that as an alliterative placeholder for adherence.

Next slide, please. Initially, the idea of convenience and the scheduling of multiple appointments at the same time was the extent of our understanding of the concept of coordination. Eventually, convenience was translated into the understanding that coordinated care means more than just making patients comfortable.

It meant and it resulted in next

slide. The convenience for the patient, which resulted in increased patient satisfaction, which contributes to the patient having confidence that the health care provider cares for the patient personally, which increases the trust the patient has in the provider, all of which next --

Increases compliance, adherence and the patient obtaining health services recommended, which promotes cost savings in travel, time and extensive care, which results in increased safety, quality of care and cost savings for the patient.

Next. This requires intentional efforts to identify opportunities to schedule visits with multiple providers on the same day, based on auditing the schedule for the next 30 to 60 days, to see when a patient's scheduled multiple providers, and then determine if it is medically feasible to coordinate those visits on the same day.

Next. To schedule multiple

procedures based on auditing of referrals, and are based on auditing the schedule for the next 30 to 60 days, to see when a patient is scheduled for multiple providers or tests, and then determine if it's feasible to coordinate those visits.

Next. In scheduling procedures or other tests spontaneously on the same day when the patient is seen and a need is discovered, and fourthly, recognizing when patients will benefit from case management or disease management or other ancillary services and working to provide the resources for those needs.

Next. This is a care coordination referral template, where a provider can, with a click of a single button, two buttons, can send to the care coordination department a request for services, including a referral to -- the SETMA Foundation, where services that the patient needs but can't afford, whether it's they can't afford a co-pay or has no insurance that covers those benefits, that we can subsidize, underwrite or pay for those services.

Next slide. Convenience and quality. It's only through this analysis we accept that convenience is a worthy goal of quality care, as opposed to it only being a means of humoring patients.

This fulfills SETMA's goal of seeking to be comfortable, providing adequate health care to our patients, and to our functionally becoming the consultant, the collaborator, the colleague to our patients, empowering them to achieve the health they are determined to have.

Next. As we learned the complexity of quality metrics, their focus and their content will change.

Next. Quoting from the Institute for Health Care Improvements High Impact Leadership study, we learned that as we move from volume to value, we are really going to change some of the subjective measures, our patient-centered measures.

For instance, with volume, we focused on patient satisfaction. With value, we're going to look at persons as partners in their care. We're going to look at with volume increased top line revenue. With value, we're continuously decreasing the per unit cost and so on.

This brings us to the whole issue of trying to determine these patient-centered metrics. CAHPS and HCAHPS both deal with those. We deal with those in our community council, when we allow patients to come in, where they have a majority vote, where they can impose us requirements that they see as being important matters.

If they don't violate the Medical Practice Act, federal or state statutes, we will bind ourselves to that referral. In regards to this process of looking at risk-adjusted quality of metrics, we really rather think in terms of data analytics, looking for leverage points to improve the quality of care for everyone, rather than trying to adjust the cost of care for -- or the quality of care for those who have major impediments or major barriers to care.

We've tried to eliminate all those barriers by first identifying them, and then finding ways whether it's financial or whether it's access to care, whether it's the illiteracy or whether it's family resistance or whatever the needs are.

It's very important, we believe, to discover what those are, to be able to measure them and then be able to quantify our meeting of those, so that we can be certain that we are more than simply in name or in number a medical home, that we are in fact in function and dynamic and spirit, a medical home.

Because the structure is one thing; the dynamic and the spirit is by far the most important thing. But it's the most difficult thing to achieve and the most difficult thing to measure. In a brief moment, that's really how we try to deal with the fact that convenience is really a new word for quality, and that ultimately, patient-centeredness, activation, engagement, where our patients really are equal partners in their care, both administratively and also professionally. We think that's important.

I appreciate the opportunity to make this brief presentation. I believe in the work that the National Quality Forum is doing, and very excited about the opportunity to watch some of our -- your development of these measures.

We actually currently measure about 65 of quality metrics for NQF. We publicly report on our website by provider name. This is our sixth year to publicly report by provider name on over 300 quality metrics. We think that type of transparency is critical. Thank you.

MS. PACE: Okay, thank you, and we're going to go on to our next presenters, and then we'll have a little bit of time, if you want to come back and ask Dr. Holly any questions. Susan and Amy are going to present on some work they're doing with the PROMIS measures, and Susan's going to start out with just kind of orienting us to what PROMIS is, and then Amy will talk to us about their new project. So Susan.

DR. YOUNT: Great, thank you, good afternoon. Next slide, please. I'm just going to provide a brief overview of the Patient-Reported Outcomes Measurement Information System, which is known as 10 Peer, funded by the National Institutes of Health multiple institutes.

Initially a road map project, and later a common fund project. This is a cooperative group Network of 15 academic institutions. The mandate for PROMIS was to create self-report measures of health across a number of domains that would be applicable to a range of chronic illnesses.

The investigators knew that we could never develop a set of measures applicable to all chronic illnesses. So we had to pick and choose as we needed to, and we adhered more or less to the WHO structure of physical, mental and social health for our over-arching domains, our framework.

These are measures that we developed for adults, for children, and many of the child measures have parent proxy measures as well. One of the unique aspects of PROMIS is the methodology that was used to develop the measures, which included mixed methods, a lot of input from patients, from general population individuals, as well as modern measurement theory, which I'll just touch on briefly.

Next please. So PROMIS has some unique features among patient-reported outcome measures, one of which is comparability, which as I mentioned, it was designed to be developed, to be applicable to a range of chronic illnesses. So therefore, you can measure fatigue and heart failure in COPD and in rheumatoid arthritis, using the same set of measures.

It's not what everyone wants to do all the time, but it can serve as an advantage. We also have a defined metric that I'll get to a little bit later. All the measures have been tested for reliability and validity, and that process is ongoing.

There's a lot of flexibility in terms of how the measures can be administered, which I'll also go into detail in a little bit and show you. So we have what we refer to as static short forms, which are just paper short forms of maybe 10 to 20 items, where every individual will answer every item, and every individual answers the same items as the next person.

We also computerized adaptive

testing for many of our larger banks, and people can customize their short forms, because every item or most items, rather, are calibrated and therefore you can take any set of items and administer them as a customized short form. Finally, one of our goals was to make PROMIS inclusive to the extent that we could. All PROMIS measures should be written at about the fifth or sixth grade reading level.

There are a number of translations available. Most are available in Spanish as well as a lot of other languages right now. We have some unique banks in terms of physical function, and as I mentioned, we have both adult and pediatric measures.

Next, please. So this is just a graphic display of the adult domain framework. It's collapsed a bit. Some of these domains, such as sexual function, gastrointestinal symptoms, even dyspnea, they have many more subdomains within them. So they're actually many more measures than just the -- this is just at the domain level, that fall within physical, mental and social health.

Next, please. This is the pediatric domain framework similarly organized. Next. So in terms of the measures themselves, as I mentioned, we have static short forms that can be administered on paper or on a computer, an assessment center which we'll touch on briefly, generally 4 to 20 items.

The typical way of administering these is that everyone answers all of the items, and they answer all the same items. We also have PROMIS profile short forms, which are measures comprised of four, six or eight items from among seven different domains for adults, or six domains for pediatric.

The yellow highlighted items are the pediatric domains and peer relationships is strictly pediatric. So what you get then, along with a single pain intensity item, which is a zero to ten pain rating, you end up with

29, 43 or 57 item short forms, and you also obtain a score within each of those domains.

Then lastly we have the PROMIS global health measure, which is comprised of 10 items. Eight of the items can be scored such that you get a physical health score and a mental health score. This is used most often when someone wants, as the name implies, just more global self-ratings of health. "In general, my health is," something like that.

Next please. So one of the really unique features of PROMIS is that we offer computerized adaptive testing. Where we have domains that have banks, which are collections, large collections of items, all of which are calibrated, and these items then can be administered adaptively if you have a computer, and adaptive administration, I'm sure many of you are familiar with this, but it's simply algorithm that selects a middle of the road item, and then the second item is selected based on how someone answers that first item.

So it's a branching algorithm that achieves a high degree of precision with the fewest items, and in general, people answer four to six items per CAT, or in other words per domain. I think our stuffing rule is set at 12. So the most items they would answer would be 12.

It does require computers. So there is that drawback. It does not require an actual CAT, however. The PROMIS metric is based on a mean of 50 and a standard deviation of ten. Sorry, got it in the wrong order there. I'll go to the metric first, and the current measures are referenced to the 2000 U.S. general population.

We have a project underway right now to recenter it to the 2010 census, and high scores reflect more of the domain or construct. So high scores and fatigue mean someone is more fatigued. High scores and physical function means the person has better physical function. So we chose the names very carefully.

Right now, we have measures in over 40 domains for the adult set of measures, and by the time the second wave of PROMIS ends later this year, we should be over 50 domains. Pediatric we have somewhat fewer, but we'll have over 20 by the time all the sites have completed their work, as well as parent proxy measures for many of the pediatric domains.

Next, please. So again, advantages to using PROMIS include improved measurement because of the precision, which can result in reduced sample sizes. Its adaptability and there is a lot of flexibility in how it's used, relatively low patient burden.

So you can administer a bank. I think our fatigue bank has 95 items in it, but the person's only likely to answer five or six items out of that, to get a highly precise estimate of their fatigue, comparability across diseases are conditions, and it's developed with NIH funds. So it is --

Next. I just wanted to mention this briefly. I know it probably -- it doesn't fit into the actual measure category, but one of the things PROMIS also funded was assessment center, which is a web-based study administration platform, that enables the creation and management of studies, as well as the administration of the short forms and the CATS.

You can go to assessment center, if you'll go to the next slide, please. There. If you go to asesssmentcenter.net, that's also where you can find out a lot of additional information about the PROMIS measures.

It's where you can download them as PDFs. You can look at the instrument library, which is a library of measures currently available, and you can set up studies there obviously, and it also included the PROMIS website for additional information, and I believe that was my last slide. Yep.

MS. PACE: Okay, and now we'll have Amy talk about a study that they're doing, using some of the PROMIS measures as it relates to some of our person-centered care concepts. Amy.

DR. EISENSTEIN: Okay. So this is, as you said, one of the studies that we're doing using PROMIS to help target treatment for patients with rheumatoid arthritis. If you'll go to the next slide, please.

So the goals of the study are to evaluate the added value of PROMIS to an existing treat to target rheumatoid arthritis treatment program, to use PROMIS to standardize the patient-centered targets of pain, fatigue, depression, physical function and social function, and to individualize these treatment targets in patient-centered language, that retains valid and responsive measurements.

So by personalizing the time that Treat to Target patient-reported end points, we were able to maintain adherence to patient values, and by using PROMIS to do so, we enable use of a common measurement framework and standard score for tracking and reporting.

Next slide, please. To meet these goals, we proposed these five objectives, to add PROMIS assessments to the existing electronic health record for rheumatoid arthritis patients, in such a way that enables individualized patient goal-setting, to evaluate the impact of a Treat to Target approach measured by -- measured clinically and through PROMIS domains to individualized patient treatment targets, to evaluate patient satisfaction with the individualized Treat to Target system, and to evaluate clinician satisfaction with the Treat to Target system.

Next slide, please. There is a little bit of background on the treatment to target. The field of rheumatology has experienced significant advances in treatments, and an enhanced understanding of optimal treatment strategies. Treat to Target is an international initiative to define rheumatoid arthritis treatment targets and recommendations, to measure disease severity, and encourage earlier diagnosis and optimized treatment.

There is a widespread support globally from the rheumatoid arthritis community. Treat to Target has succeeded in establishing international consensus in defining targets that will be well-accepted and applicable in daily practice.

Despite this, there remains a wide heterogeneity of outcome expectations and patient concerns, and patient-centered outcomes have typically not been considered when implementing Treat to Target strategies in clinical care, and we know that patients and physicians consider different aspect of disease when making treatment decisions.

Next slide, please. So total will be talking to like 120 patients who have been diagnosed with rheumatoid arthritis. We will include patients with low disease activity who believe that, from their perspective, they have not reached their personalized goal of disease control. This will help to identify a population in which there is disconnects between the patient and the physician in the shared decision-making process.

For those who are in high disease activity at the start of the study, we seek to determine whether the addition of the PROMIS assessments will facilitate achievement of a shared treatment target, and allow for improved integration of the patient's perspective into the steps required to achieve that goal.

In terms of methodology, we'll be talking with patients every three months over the course of a year. Assessments include clinical questionnaires, the PROMIS computer-adaptive testing instruments, open-ended quality of life items, and then the patients will be asked to prioritize the PROMIS domains, and that will be shared with their physicians.

From there, they'll also be asked to choose five of the items that are most meaningful to them, in terms of their concerns within their disease status, and those will also be tracked over the course of the year and shared with their physicians.

Next slide, please. So this is one of only two studies that we're aware of using individualized patient-reported outcome assessment in rheumatoid arthritis. We're actually working with the PIs of the other study as consultants, so that we could advance this area harmoniously with them.

This application of patient-reported outcomes is both individualized and standardized, which is only possible through use of the IRT analysis and qualitative clinical input from patients. That's it.

MS. PACE: Okay, thank you. So Amy,

maybe you could talk just a little bit more of what this might look like in a practice situation, because I think that will help bring it to life a little bit, in terms of having patients actually identify what symptoms and then what questions from the PROMIS. Could you just talk a little bit about that, and then we'll ask the Committee if they have any questions.

DR. EISENSTEIN: Sure, sure. So that in terms of their using the PROMIS items, their symptoms won't necessarily be specified. They'll looking at each of those five items, physical function, fatigue, depression and a few others, and we have written up cards for them which are an explanation of what each of those domains, kind of examples of what they are.

So for example, physical function domain. We say "Physical function refers to your ability to carry out activities that require physical action. The activities can range from daily activities, such as brushing one's teeth to more complex activities, such as household chores or yard work."

So they'll be given examples of each of the domains just like that, and then asked to choose which of the domains is most important to their disease management progression.

So from there, after they choose which one of those is most important, they'll be given a list of all of the items. Some of the domains have closer to 20 items within them, and some get up to 40 or 50 items.

They'll be asked to review those items, and choose the ones that are specifically most concerning to them. So now some of the -- this allows the physician to see, as an example here in the physical function domain, some of the items could be are you able to hold a plateful of food, versus are you able to go up and down stairs at a normal pace.

Some of the clinical insight from the physicians doesn't necessarily get to that detail or that understanding of where a person is, in terms of what's important to them and their quality of life. Does that help?

MS. PACE: Yes, thank you. Okay. So we have a few minutes. If anyone has any questions or comments for Dr. Holly or Susan and Amy, Drs. Yount and Dr. Einstein, feel free. Dave.

MEMBER deBRONKART: So first of all, Dr. Holly, are you still on the line?

DR. HOLLY: I'm here, yes sir.

MEMBER deBRONKART: I want your slides. I'm serious, and I mean to me, it's the ultimate answer to all the people who say it can't be done. I'm serious. I want to spread the word through the patient community as much as we can, because sometimes patients can bring new ideas to their doctors. Who knew?

DR. HOLLY: Oh absolutely.

MEMBER deBRONKART: No seriously. I'm not being a smart alec. Part of my --

DR. HOLLY: Oh no. I totally agree.

MEMBER deBRONKART: Part of my core message of let patients help is not just clinically, but in all sorts of things. I loved all the presentations. Amy, I wonder how did you settle on the RA? It's a field that I know some people with that disease. I'm just curious how you settled on it?

DR. EISENSTEIN: Well first, I will say I actually joined this department after the project was started.

But based on my understanding is Northwestern participated in one of the -- in the development with the Treat to Target methodology. So they were already active in that area when it came up that they were lacking the patient input, and then just through collaborations, this came up and was developed.

MEMBER deBRONKART: So I ask because

are you aware that RA is one of the diseases, if not the disease that is the worst in terms of clinician arrogance and obnoxiousness? I'm serious. No, serious. No. I mean it as a real question, because I know some people who have not mentioned your work, and I think would be very interested to know.

DR. EISENSTEIN: You know, one of the things that we are working with is actually the physicians will be entering this information into the electronic health records.

So we are doing quite a bit of follow-up with the physicians themselves, to find out how much this benefitted them versus the difficulty in terms of getting it entered and tracking it over time. So we're certainly looking at that.

MEMBER deBRONKART: I'm just curious. So I'd love to know -- I guess today's not the day, but I'd love to know what the genesis was of settling on that particular disease.

Because for instance, the famous RA Warrior blogger Kelly Young, talks about how, in great detail; I mean she's very, very competent scientifically, talks about how what the clinicians were taught to measure, aside from not being what patients care about, which is what you're talking about, but is also, in many cases, demonstrably scientifically wrong.

I'll just -- in closing, I'll just read a few sentences from a blog post by a rheumatologist in Indiana named Larry Greenbaum. "If your practice is like mine, you probably don't bill for consult Level 5 very often.

It's the most expensive level of care. A 75 year-old man came to me with RA, didn't bring many records, but I spent a very memorable hour with him. I charged him Level 5 for taking so much of my time, bad-mouthing his previous doctors and incessant whining."

Down at the end, he says "He had a

deformity of his big toe due to a claw toe surgical repair that had gone awry, and just for good measure, he spent some time bad-mouthing that doctor." The title of this blog post literally is "Kiss my ..." The Rheumatology News posted it and then after patient complaints, they took it off the index, but they would not remove the post.

So this is a profession that is flagrantly disrespectful. So you can see. You can tell the alarm bells that went off here. I don't know who's in a position to tell them to knock that crap off, if anyone, and but anyway, so I'd like to talk more after that.

MS. PACE: Right. But you would agree that this is a great approach, of sitting down with the patient and --

MEMBER deBRONKART: Oh positively. This is exemplary.

MS. PACE: Right.

MEMBER deBRONKART: And I just don't

know if everybody in that patient community knows that it exists.

MS. PACE: Good point.

DR. HOLLY: Yeah. There's another -- this is Larry Holly. Another condition that fits that same model and it's Parkinsonism. PROMIS would be fabulous for helping understand the desperate need for autonomy and personal integrity, with patients with gradually progressive disease, that can still allow for a successful ending.

But rheumatology is -- RA is an excellent example. Another would be, I think would be Parkinsonism.

DR. YOUNT: This is Susan Yount. If I could just interject. We were involved in the development of another measurement system called Neuro-QQL, which was also NIH funded, which was developing very PROMIS-like measures. I'm sure the Neuro-QQL community wouldn't appreciate that I said it that way.

But they're using the PROMIS

methodology to develop measures for a number of neurological conditions. So we do have that as well.

MEMBER deBRONKART: Great.

MS. PACE: Ethan.

MEMBER BASCH: Just briefly. You know, there's been a fair amount of interest in innovating patient-reported outcomes and care processes and to EHRs. It was, you know, tied in, I think, to the topic of a prior panel for NQF, and has been an area that PCORI has been recently interested in.

I think that one of the real challenges is around work flow, sort of entrenched workflow, and it's really -- it's just not built into the provider day to review the patient-reported outcomes, to sign off on it and to act upon that information.

So you know, it's on point and off point to what we're talking about today. I do think it's an important part of being patient-centeredness in communication. But I think that we have to bear in mind that it's very challenging to get providers to look at these things.

DR. HOLLY: May I comment briefly on this? This is Larry Holly, because we -- beg your pardon?

MS. PACE: Go ahead.

DR. HOLLY: We have really addressed that issue over the last 14 years in our customized EMR, because we believe that quality metrics ought to be incidental to excellent care. They ought to be collected and reviewed, not as the intention of care but the incidental.

As a result we have disease measurement tools, clinical physician support that providers utilize in providing excellent care, coincidental to that and in the background. That data is collected and organized without the provider doing anything. At the end of the visit, the provider can review that, if he or she chooses, and can then fill in anything they didn't think to do.

Invariably, over time, it just becomes a natural part of their flow. For instance, with congestive heart failure, making sure you document the subjective and objective evidence of fluid overload. Initially, you might use the clinical decision support, in order to make sure you deal with those.

Ultimately, that just becomes a part of your own the way you deal with patients. I think it's possible, and unfortunately EMRs are built by technicians who build it for their specifications, and it's not built by clinicians who build it in order to make it easier for them to do it right, but not do it at all. It is possible to do. I think we've successfully done it and have demonstrated that, and I think others can do it.

Everything we do is for free on our website. We sell nothing and people can take it and use it. But it is possible to do, in the context of a busy clinical practice and ordinary workflow.

MS. PACE: Okay. Why don't we start here? Jennifer, Bruce, Ellen and Troy, and then we'll close out this session.

MEMBER EAMES HUFF: Sure. I have a question for either Susan or Amy regarding PROMIS, actually a couple of questions. One is could you say how widespread this is used in clinical practice, to get a sense of where it is or isn't being used, and then talk about the facilitators for having this in use in clinical practice, and some of the barriers.

DR. YOUNT: Wow, that's a good question and a complex question. It's really hard for me to answer the question comprehensively, because we don't track who uses PROMIS. Early on, we decided to make it as freely available as possible without barriers, which is also a big obstacle when you present like this and then people ask questions like that, and we don't have the information to give you.

I know that Cleveland Clinic has been using it for a few years in their clinical care, and I actually don't know -- I'm sure there are other places doing it. I just can't reel them off to you. I think one of the facilitators is having the IT infrastructure for the administration, and maybe the scoring, the graphical displays and so forth.

So I think that's a facilitator, and not having that is potentially a barrier, because then you're left with paper forms and that's the age-old problem of how you score them and get them into the medical record or whatever. So I'm sorry, but that's the best answer I can give you.

MEMBER LARSEN: So this is Kevin Larsen. I can take a little bit of it. But go ahead too. So under our measure development contracts at HHS, we're developing a whole suite of patient-reported outcome measures. It's a really key area of federal measures. It's a priority.

So because of that, we have to have a lot of kind of field intelligence about where these are deployed, so that we can know how they work in clinical practice. So we know that there are a number of organizations and states, in fact, that use a lot of patient-reported outcomes. Minnesota, for example, has a number of patient-reported outcome measures in their measurement domain.

They haven't incorporated PROMIS yet, although in the meaningful use program, we have a number of measures already in federal programs that do incorporate PROMIS, especially the PROMIS global assessment, in current measurement statute.

We also are in the process of discussing across HHS prioritizing PROMIS as a primary instrument for patient-reported outcomes, so that we have a coordinated free measurement system around PROs.

So, you know, if I were a betting person, I would bet that that's the kind of thing that we would be likely to commit to as a department.

MEMBER FORREST: Just briefly Susan, Chris Forrest here. You might want to talk about the Epic initiative.

DR. YOUNT: Chris, you can probably talk about it better than I can. I know that PROMIS is in Epic, in the electronic health record. If an institution -- I believe an institution has to have purchased that module. I don't know if you want to add more, Chris.

MEMBER FORREST: I would -- I just wanted you to be aware that Epic actually has now created a patient-reported outcome module, and embedded PROMIS measures into that patient-reported outcome module. The PROMIS Technology Center is working with Epic to go from short forms, four or eight item questionnaires, to computerized adaptative tests.

The reason why Epic did this is because of demand from its users. So the advantage of having the PROMIS measures in Epic is that they get standardized in terms of the way they're stored in the database, and also it just makes it easy for clinicians to use.

There are a lot of other bells and whistles which I can go into some other time about the application. It actually is quite nice.

MEMBER LARSEN: This is Kevin again. Like I said, in answer to your question, we do know of a couple of institutions, large institutions across the country that are deploying PROMIS as a routine part of patient care delivery, though not in a specific domain or framework. So for partners, for example, a couple of their large practices have said we're going to measure PROMIS at each and every -- for each and every patient that receives care in our system.

Align Health System in Minneapolis, Cleveland Clinic, Northwestern, there are a few that have done this in certain components of their clinical practice, as a routine part of the care delivery process, with the idea that they can then get more sophisticated and really be honing and targeting all of their system to key patient-reported outcome.

MS. PACE: Troy and then Sally.

MEMBER FIESINGER: Okay. Thank you Dr. Holly. Now I know where the slides my boss is showing about how to publicly report our quality measures came from, because I recognize that screen from earlier this week.

So a couple of questions on PROMIS, one technical. Can y'all run reports by population, by patient group? Second, how do you communicate this to patients and use it in that form, and as a provider I'm thinking I spend a lot of time doing Medicare physicals.

This gets at the core of what I want to find out about these people, which is going to be how do you present and organize it by population, how easy is it to get the data out, and then what do you do when trying to communicate with the patients?

DR. YOUNT: If you're using PROMIS with an assessment center, the data always belongs to whoever set up the study. It's not our data. So you can do a data export at any time you want. It's really easy. You literally just go in and click a button.

Then what you do with those data is then up to you. Those aren't reports. That's just the database, and I forget some of the other aspects of your questions. I'm sorry. Can you repeat them?

MEMBER FIESINGER: Yeah I guess can I generate a report to show a patient? Can I generate a report to show fellow physicians, supervisors, hospital administrators, whomever I want to show it to?

DR. YOUNT: On an individual patient level, yes. We have these CAT reports that are heat maps. So you can actually go to assessment center or the PROMIS website and do the CAT demo, and then see the report that would be generated for the domain that you select.

I'm not aware of any ability to generate it for groups of patients, more than one at a time right now.

MEMBER FIESINGER: Thank you.

CO-CHAIR OKUN: Hi, this is Sally Okun. I'm calling from PatientsLikeMe. Thank you for your presentations, and I just wanted to let the group know that we actually are also in collaboration with PROMIS researchers, to work on --

We have a platform on our site that's funded by the Robert Wood Johnson Foundation. It's called the Open Research Exchange Platform, and we're creating patient-reported outcome measures with external researchers and with patients collaborating with us in that process.

One of the things that we recognize is much of our work is really condition-specific. So we're trying to benefit from all of the great work that PROMIS has done with some of more generic measures, where we can find some alignment against the condition-specific one.

So we're really hoping that the two together will actually give patients a real opportunity to give that kind of data, and possibly get that kind of data collected prior to a visit, and they can bring that in with them as they come into this.

So the work -- integrating that into the work flow could get more -- get a little bit easier, from the patient perspective.

MS. PACE: Okay. Well thank you to -- oh, Ethan, yeah.

MEMBER BASCH: Yeah. I just wanted to make a quick note that, you know, integrating patient-reported measures into care is really just an improvement in the way that providers already do things, right? I mean as a provider, I'm supposed to talk to my patients and do a review of symptoms and understand what they're experiencing my, our shared decisions.

We know that introducing patient reporting into that process improves the precision and the reliability, and the management of those things being measured, from multiple studies that have been done.

So you know, to me really the argument here is that this is a way both to make our current processes more patient-centered, but also actually to improve, you know, the precision of what we're already doing.

It's not like we're reinventing the wheel here. We're just trying to do what we already do better, and patient-centeredness helps us to do that. You know, the second piece to that is it would be -- my understanding is that a provider can actually bill against a patient-reported review of symptoms.

So in a scenario where an EHR has the ability to collect information from the patient, that goes to the provider. The provider can sign off on that in the note. That can actually be billed against, from CMS' perspective.

MS. PACE: Okay. Well, I'd like to thank Dr. Holly, Dr. Young and Dr. Einstein -- Eisenstein for sharing their work with us. We really appreciate it, and thanks for taking time out of your day to get on with us. Thank you.

DR. HOLLY: My pleasure. Thank you.

DR. YOUNT: Thank you.

Small Group Work

MS. PACE: So what I'm going to do briefly is tell you what we're going to do in our small groups, and then we'll take a break and move to our small groups.

So in your packet, you have some

instructions and the small group list, and so I'm just going to go over a little bit about what we're envisioning to happen in the small groups. The goal is -- we've broken these into four groups. We're broken into four groups.

Each group will look at two measure concepts. So Group 1 is going to do Concepts 1 and 2; Gene Nelson will be the leader and one of our staff people, Karen Johnson, will be with that group.

Group 2 is Concepts 3 and 4. Michael Lepore is going to be the leader and Mitra will be the staff person.

Group 3 is Core Concepts 5 and 6. Bruce Leff is the leader and Camille from our staff will be the staff person.

Group 4 is Concepts 7 and 8, and Troy is going to be the leader and Wendy will be the staff person. We'll tell you, Groups 1 through 3 will stay up here; Group 4 will go to another room with Wendy on this floor, but in another area.

So basically what we want to come out of those groups with is some ideas of measure concepts related to those core concepts. We've identified a process that we think will work, and the staff person can help with this if there's any confusion. But I'll just review it quickly.

So what we'd like you to do when you go to those small groups is individually, and you'll have some handouts specifically for the group.

But basically start with looking individually, reviewing that measurement framework for the two concepts, and just thinking for yourself, what are some measure concepts that you think would be important to measure for that particular core concept.

And again, you can think about, you know, the core concept as it is or with slightly revised wording. But I think we are pretty well-understanding what the essence of those core concepts are. We'd like you to write that on a little post-it note, which you'll have in your groups, and then if any of those measure concepts are things that you think would be applicable for the label idea, to just indicate label on it.

Then we'll have you post those on a paper, on a flip chart under structure, process, outcome. Don't get too hung up about that. If you don't know, just put it up there, and then really to take five to ten minutes to do that. So it's a fairly quick -- you know, I know you've all been thinking about this for quite a while, and as we've been sitting here and talking.

So to get those, you know, two to three concepts that you think are really important, that we should consider for measurement. Then we'd like to have your group discuss those, that people have recommended, and we would ask the person who suggested the measure concepts to describe it, and to think about, you know again, describe what you think should be measured.

You might think about what patients would be included. Would it be all patients or specific patients groups? If you have any idea about data source or who's the entity being measured?

We've had some of those discussions, and again, these are not imperative, but if you have some ideas about those to explain, and then also why you think I should be considered for a national standard for performance measurement, or the label idea, and to have discussion among your group.

Then you'll go through, after you've discussed the suggested core concepts, we'll ask you to vote on them within your group. We'll give you some dots. You can pick your top four in each concept, and those, you know, the ones that have the most votes will be the ones that hopefully your group agrees are the most important to bring back to the larger group.

Then we have some worksheets, to just fill those out, so for when we report out to the larger group. So again, I know that's a lot to think about right now. Your staff person can help clarify anything, and certainly the leaders will facilitate the discussion. Bruce.

MEMBER LEFF: So as a leader, I definitely need something clarified.

MS. PACE: Right.

MEMBER LEFF: So it feels to me, tell me if I'm -- sometimes this is jargon.

MS. PACE: Right.

MEMBER LEFF: So our 1 through 8 at some level to me feel like high level domains of measure. Is that a fair statement?

MS. PACE: Right.

MEMBER LEFF: If I'm hearing you correctly, it sounds like you want us to get to the level between a domain and an actual measure. Sometimes those are called standards or elements, the standards, quality standards.

MS. PACE: Well --

MEMBER LEFF: So for instance, if we were -- if a domain was quality of life, so not really one of our eight, but just quality of life, a domain under that might be symptom control, right, before you actually get to a measure of, you know, improving depression symptoms, right?

So are we in that middle range and you're asking for constructs around those?

MS. PACE: So I think what, and maybe we can -- if we look at the measure framework, to just get some ideas. So for example, your group will be looking at, which ones, family and information.

So if the core concept is that, for example, my family care partners include those I choose, and their role is supported by other care partners, you know, that would be kind of the experience or potentially a patient-reported experience outcome measure.

But are there other things that, for example, are processes that support that? Are there structures or systems that would support the patient and family experiencing that core concept? So you know, I don't know if there's levels.

But it's really to start thinking about if that truly is what the patient experience should be in ideal person- and family-centered care, the patient and family, what would we do to assess whether that's really happening and, you know.

So you know, the first obvious one is the experience with care. But there may be others, and that's what we want your group to kind of grapple with.

MEMBER LARSEN: Yeah. I would say in the measure development world, we call them "measure concepts," you know. We're clear that there's a whole process by which you go from a general concept to a specific measure. We're certainly not looking for a specific measure, but something more than just a framework or, you know, the --

So if I think about Dr. Holly's work, it would be the number of or the percent of times that a patient receives all of their care on one day, you know. That's his --

(Off mic comment.)

MEMBER LARSEN: In the measure world, that's not really a measure yet.

MS. PACE: That's really a measure concept.

MEMBER LARSEN: That's a measure concept.

MS. PACE: Because in the measure world, then you have to get to the very detailed data.

MEMBER LARSEN: In the measure world, there's a 15-page document that tells you exactly how to make that happen.

MS. PACE: Right. So you're right. Some of this is terminology, and how deep you get into measurement. But the point is to really think about what could be measured or should be measured. It's not really just what could be measured; it really is what should be measured, because if we focus on what could be measured, we end up with measures we really don't want or patients aren't interested in.

MEMBER DUBOW: So jumping ahead to the endorsement process, we're going to -- these measures clearly are going to be exposed to the criterion that is evidence. How much in this space do we know about evidence for structures and processes that support the outcome that we're seeking?

Because I think that these are all intuitively correct; they seem to have face validity. But frankly I am not familiar with the evidence that would meet the test of the endorsement process. So what do we do about that?

MS. PACE: Well, I think that's a good point, and that's why I was bringing up, you know, is there evidence that would say that this rises to the level that you say we want a national performance measure, which means everybody should be measured against it and be doing it the same way.

So that's where, you know, the outcome of what we really want the person to experience is probably first of all more relevant to patients, and we have the patients and patient representatives in each group. So definitely do a test with them, as you're thinking of these measure concepts.

But again, the other thing with processes is that there's probably lots of different ways to achieve the same thing, and you know, there are system contexts, there are patient contexts. So you know, I think it's a good question and I think you're going to have to grapple with in the group, you know, whether process measures may not be the way to go, especially in this space. But Kevin.

MEMBER LARSEN: I can tell you the way we think about it at HHS, as we build and prioritize measures. So that we definitely hold a high bar for evidence and research. But we also know that in the National Quality Strategy there are some domains that are very important, and if we have -- it's sort of a Bayesian analysis.

If there isn't much evidence in that area, we're willing to take more risk for some measures with some evidence of face validity, then we are on a new measure in an area where that is heavily -- that has a heavy amount of science and research.

So it's not to say that we don't need some evidence. But we have a sort of nuanced amount of evidence that we're willing to do in these important measure gap areas.

MEMBER DUBOW: Okay. So I have to tell you that there's -- I'm sorry. There's a board committee now that's looking at the next steps to flesh out the consensus process, and already the question about scientific evidence and what's good enough has bubbled up to the top, no surprise.

But I think that we need to be mindful of those challenges, because the tension that happens at NQF, particularly around endorsement, has to do with exactly that, what's good enough. Are we driving resources to processes and to structures, for that matter, for which the evidence base is unknown?

I'm okay with equivocal, but unknown? I think we need to be very, very thoughtful about this, because it's only going to come back to bite us later. So I think we have to be really careful about it.

MEMBER WALLING: I also just was curious if we'd have the chance to comment just on the framework in general too. One question is just because process measurement always has its limitations, but it also has its benefits.

So for example in measurement, if you only get outcomes back about your patients, it's often difficult to figure out how to improve those outcomes, whereas process measures sometimes give more actionable direction to what to improve, especially if they're linked, the process and the outcomes.

So you know, if we're being broad I would like to know that we're including as many potential good areas for measurement, and not cut out potential areas where there could be a good impact on patient care. Does that make sense?

MS. PACE: Sure. I think, you know, and again, this is something that you'll have to discuss within your groups. You know, the other -- because we really want to identify priorities and, you know, there probably are hundreds of processes and structures that would support person-centered care.

So you have to think about what do we want to invest performance measurement in? And so, you know, just because we may not want something for a national performance measure doesn't mean it wouldn't be very valuable from an internal quality improvement, and figuring out where you need to improve.

So I'm not saying to cut anything off. I'm just saying that, you know, our goal is eventually to prioritize and help identify where to direct resources to develop performance measures. If we have hundreds, that's not going to be that useful or feasible, in terms of accomplishing what we want.

But definitely, you know again, each person to really identify what they think is most important, the group discuss those. You know, when we come back to the larger group, we'll be discussing them all of them as a larger group, and eventually have to make some, you know, prioritize and make some recommendations that may fall into shorter term and longer term.

So you know, right now, you know, it's open. Think about it, and just really discuss it in your groups. Yes.

MEMBER WALLING: Question. I know the word "patient-reported outcomes" is often used. I've seen patient-reported process too. Are they -- how are we thinking about patient-reported outcomes in terms of --

MS. PACE: When we had our project, they were really patient-reported outcomes in those domains of, you know, the functional status, quality of life, symptom, symptom burden, experience and health-related behaviors.

So yes, you're right. There could be a survey that says did you get your flu shot, and that's patient-reported data, right, and you know, I don't know that I need to say anything more about that now. I mean it's not off the table, but again, you know, with any measure, you know, what's the best data source, and do you want to, you know --

Just as an example, and this came up in our patient-reported outcomes project, there could be something very important to patients. But if you don't -- if there's another source of the information that is just as good, then you don't have to ask the patient to spend the time filling out a survey about it.

So again, you know, we need to think about, you know, the burden and who's the authoritative source for any particular information.

MEMBER WALLING: Just to clarify, the example I'm thinking of is, for example, process measures on whether patients feel that their symptoms are assessed and managed in the way that they want them to be managed.

So it's not -- so it's a patient-centered measure, that we actually have looked at it in medical records and patients, and you get slightly different, you know, results.

MS. PACE: So we don't need to get hung up on whether it's a structure, process or outcome. You know, obviously if it's evident to note that, but you know, the main thing is really what should be measured given our discussion about what is person- and family-centered care. Okay.

So we'll take, you know, if you need to take a break -- yes, Dave.

MEMBER deBRONKART: So tiny but vital one. You just triggered something. I hear so often people say that we could ask did you get to say everything you wanted to say, right, and that could include -- I mean I know of people who had five things they wanted to bring up and/or conditions, and they only got to do two and the meeting was shut off.

Or were you interrupted a lot? You know, the famous 17 seconds between interruptions. Is that all fair game?

MS. PACE: Yes.

MEMBER deBRONKART: And I don't even know if that's a process or did you --

MS. PACE: No, it's fine. It is totally fine, and I think -- I really think that Dave's challenge to think about this, you know, what's the simple question we could ask patients, is very important for all of the groups to be thinking of, and yes, that would totally be fair game.

CO-CHAIR OKUN: Just one other clarification I'd like to make, because I think that's a really good point, and that may apply to one concept but maybe not another and that sort of thing. So I guess -- and then we're not necessarily then charged at all with thinking about whether that -- there's a measure that exists for that yet.

That's where you then take the things that we say. This should be part of a patient, family centered care concept. We see it should be in this particular concept that we've come up with, and then you're going to be taking that and sort of testing that against what exists already to measure it, or if that's a gap we've identified.

MS. PACE: Right, absolutely. We

know that some of, you know, the CAHPS measures actually have -- or the CAHPS survey actually have a lot of individual measures. In the measurement framework, we identified a few that related to the core concepts, and there's, you know, many others.

So we can look to see if there's something that's already measuring that. But the idea today is really to start thinking about what should be measured in this space, and then we can see if there's already existing measures which will help us also.

MEMBER FORREST: I'm going to go back to a comment I made earlier. So if you take a domain broadly speaking, like respect and dignity, there are -- that can be fleshed out and there are ways of measuring that. That's at the experiential level of the patient.

If we only focus on that though, we are going to be missing the measures of the system that enables that. I wonder when we're going to get to that, for example.

MS. PACE: Right, and if you -- now, I mean because that would be the structural, the system measures. So if there are things that really are system-related, that really support that happening and you know --

MEMBER FORREST: So we should be thinking about like a driver diagram. So there's -- ultimately in this person-centered care, respect and dignity is one of those components, and then there are system level domains that relate to that.

MEMBER LARSEN: Yeah. I would say absolutely. You know, one of the measures that I did in my health system was what percent of a nurse's shift did she spend at the patient bedside, versus anything else. So that's a structural measure or a process measure that absolutely drove patient-centered care.

We were -- focus was one of our number one priorities for inpatient nursing, to get the nurse in the patient room talking to the patient as much of her shift as possible. So I would say those structural measures are absolutely on the table.

MEMBER BASCH: So there could be multiple measures, some could be patient-reported, some are process measures for each of these individual domains or concepts.

MS. PACE: Exactly. So I know that's kind of fuzzy, but we'll work with it. I know you all have great ideas, and we'll trust you to work this out in your groups, and given the time, what we're going to do is not try to do report-outs today, because we want to give you enough time.

So we really will spend the rest of our day until our adjourn time is 5:15 in your small groups, and then we'll do report outs in the morning and just our schedule tomorrow some. But we wanted to give you enough time and not have you hurry.

So with that -- okay. So Group 1

will be at that end of this room. Group 2 here. Group 3 in the back, and then Group 4 is going with Wendy to another room, okay. All right, thank you.

And operator, I guess we should -- Wendy, I guess we should just go ahead and close the webinar. For those on line, we're going to go ahead and close the conference call, since we're not going to reconvene as a large group, and we will also end the webinar at this time.

(Whereupon, at 3:30 p.m., the meeting was adjourned to small group session.)

C E R T I F I C A T E

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

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

Neal R Gross

Court Reporter