NATIONAL QUALITY FORUM

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ALZHEIMER'S DISEASE AND RELATED DEMENTIAS COMMITTEE

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MONDAY
JUNE 2, 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 9:30 a.m., Penny Feldman and Eleanor Perfetto, Co-Chairs, presiding.

PRESENT:

PENNY FELDMAN, PhD, Visiting Nurse Service of New York, Co-Chair
ELEANOR PERFETTO, PhD, University of Maryland School of Pharmacy, Co-Chair
MARY BARTON, MD, MPP, National Committee for Quality Assurance
BARBARA BAYLIS, RN, MSN, Providigm
RYAN CARNAHAN, PharmD, MS, BCPP, University of Iowa College of Public Health
SUSAN COOLEY, PhD, Department of Veterans Affairs *
CYNDY CORDELL, BS, MBA, Alzheimer's Association
LYNN FRISS-FEINBERG, MSW, AARP Public Policy Institute
MURRAY GROSSMAN, MD, American Academy of Neurology
RAZIA HASHMI, MD, MPH, WellPoint, Inc.
MATTHEW JANICKI, PhD, University of Illinois at Chicago
KRISTIN KAHLE-WROBLESKI, PhD, Eli Lilly and Company

KATIE MASLOW, MSW, Institute of Medicine
SOPHIE OKOLO, MPH, National Association of States United for Aging and Disabilities (for Martha Roherty)
DAVID REUBEN, MD, UCLA Division of Geriatrics, David Geffen School of Medicine
MARK SNOWDEN, MD, MPH, University of Washington School of Medicine
WILLIAM STAPLES, PT, DHsc, DPT, GCS, CEEAA, University of Indianapolis
ERIC TANGALOS, MD, FACP, AGSF, CMD, The Mayo Clinic
JOAN TENO, MD, Brown University School of Public Health
YAEL ZWEIG, MSN, ANP-BC, GNP-BC, NYU Pearl Barlow Center for Memory Evaluation and Treatment

NQF STAFF:

JULIET FELDMAN
KAREN JOHNSON
ELISA MUNTHALI
TAYLOR MYERS
WENDY PRINS

ALSO PRESENT:

CILLE KENNEDY
D.E.B. POTTER
GEORGE VRADENBURG *

* present by teleconference

A-G-E-N-D-A

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

9:32 a.m.

MS. JOHNSON: Okay, good morning, everybody. Thank you so much for joining us today at what I think of as our dementia meeting, but it is the Alzheimer's Disease and Related Dementias meeting where we are going to try to prioritize gaps for future measure development.

So thank you so much for all of your work so far. I know a lot of you have looked at our materials and offered a lot of feedback and I appreciate every bit of it.

And I hope today is informative and useful to you all. I know it will be to us.

So again, I think I got to talk to most of you. I'm Karen Johnson. I am the senior director here at NQF. And I'm acting as the, I don't know what they're calling me on this project, advisor on this project, something like that. But anyway, I am kind of making sure that we hit all the content so I'm the content expert for this one.

And we also have Juliet and Taylor and they will introduce themselves as we go around the room.

But for now I'm going to hand it over to our co-chairs. I think if you don't already know them you will soon. This is Penny Feldman and Eleanor Perfetto. And I want to hand it over to them to introduce themselves and take us through the day.

CO-CHAIR FELDMAN: I'll start. I was not at our first face-to-face meeting because I was getting a new hip and I'm glad to say I've got it and I'm here. So I'm very excited about today.

And I'm the senior vice president for research and evaluation at the Visiting Nurse Service of New York. And I have an appointment also at Cornell Medical School.

This is an incredible group that's been so participatory in response to all the emails that go out. And we've just done so much in advance and made so much progress that I'm really looking forward to a very productive two days.

CO-CHAIR PERFETTO: Yes, thank you, everyone, for your participation. I think this is going to be an exciting meeting.

There are some of us who are here who participated in some of the previous work that was done to this which you'll hear us mention ADMII every once in awhile, the Alzheimer's Disease Measurement Improvement Initiative. And so some of the materials came from there.

So I want to thank you for not just the contribution that you've made over the last six months to this project but also the several years of work that's gone into all of that that got us to where we are today.

And so we're going to go through a little bit of an introduction. Penny, you're going to handle goals? Are we going to go around first? Okay, we're going to go we're going to go around first.

So let's start with Katie. Katie, are you settled in enough over there? We'd like people to give their name, their organization that they're affiliated with and a little background on what got you here today, why you're here.

MEMBER MASLOW: Okay. I'm Katie Maslow. I work at the Institute of Medicine in D.C. And I was involved in ADMII that Eleanor just talked about. And I've been thinking about Alzheimer's and dementia measures for a long time.

MEMBER GROSSMAN: Hi, my name is Murray Grossman. I'm a neurologist at the University of Pennsylvania. I was nominated for this by the AAN, the American Academy of Neurology.

I have a clinical practice looking at patients with Alzheimer's disease and other neurodegenerative conditions and I do lots of research on these conditions with cAMP biomarkers.

MEMBER STAPLES: Good morning, I'm Bill Staples with the University of Indianapolis and also at the Center of Community and Aging at the University of Indianapolis.

By training I'm a physical therapist and I work a great deal with people with Alzheimer's disease. And I am currently the president of the Academy of Geriatric Physical Therapy.

MEMBER CORDELL: Good morning, I'm Cyndy Cordell. I'm pleased to be here with all these esteemed members. I am the director of healthcare professional services for the Alzheimer's Association.

MEMBER TANGALOS: I'm Eric Tangalos, professor of medicine at Mayo Clinic.

MS. JOHNSON: Yes, and the way these microphones work, if you would just make sure you mute yourself. We can only have a couple of mikes on at the same time.

MEMBER TANGALOS: I'll try again.

Okay, Eric Tangalos, professor of medicine at Mayo Clinic. Eight years with the National Board of the Alzheimer's Association. And I sit with the NQF Common Format Steering Committee.

MEMBER CARNAHAN: Ryan Carnahan, University of Iowa College of Public Health. I'm an epidemiologist and psychiatric pharmacist and I do work in dementia care quality improvement.

MEMBER BAYLIS: I'm Barbara Baylis. I'm a registered nurse. I've worked on the provider side providing services to dementia patients in multiple site units.

I'm currently director of accreditation for Providigm for quality management system. Thank you.

MEMBER ZWEIG: Hi, my name is Yael Zweig. I'm a nurse practitioner at the New York University School of Medicine and I see patients clinically in our memory-specific department, the Pearl Barlow Center. And I'm a nurse representative nominated by the American Nurses Association.

MS. PRINS: Good morning, everyone. I'm Wendy Prins. I'm a senior director here at NQF. And I've been sort of peripherally observing all of the gaps projects and trying to make some connections between them which I think this project is really ripe to do. So I'm really looking forward to it.

MS. POTTER: I'm D.E.B. Potter from the U.S. Agency for Healthcare Research and Quality. I also work two days a week at the Office of the Secretary. I'm the HHS subject matter lead for this project and I work on several projects specific to vulnerable populations to develop quality of care measures.

MS. FELDMAN: Good morning, my name is Juliet Feldman and I am the project manager for this and two other projects at NQF.

MS. MYERS: Good morning, Taylor Myers, administrative assistant. And I'm supporting this project as well as two others here at NQF.

MS. KENNEDY: I'm Cille Kennedy and I'm from the Office of the Assistant Secretary for Planning and Evaluation at HHS. And I have the honor to be the government task lead for the projects under this umbrella contract of which -- I mean, they're all stars, but this is today's star group.

And the reason, first of all, that we're all stars is that you are here. And you are here because the whole contract is based on the fact that we're getting advice from the outside to the Department.

And then I have to thank D.E.B. for coordinating very well this project and NQF. I mean, it's just been smooth and fluid and extremely productive so far. And I look forward to two more wonderful days. So, thank you.

MS. OKOLO: Good morning, I'm Sophie Okolo and I'm with States United for Aging and

Disabilities. I'm here on behalf of the director, Martha Roherty. Thank you.

MEMBER JANICKI: I'm Matt Janicki. I'm with the University of Illinois Chicago, the Rehabilitation and Research Training Center on Developmental Disabilities and Health. And more importantly I represent the National Task Group on Intellectual Disabilities and Dementia Practices. So I guess I'm the token person representing that group.

MEMBER HASHMI: Good morning, I'm Razia Hashmi. I'm a family physician and geriatrician. And I am here representing WellPoint Anthem Blue Cross Blue Shield Association, so a managed care medical director.

My connection to geriatrics as I was telling Penny, my geriatric career started out with a collaboration with VNS and home visits in Harlem and the South Bronx.

And you know, I don't even work in

the Medicare business so I was wondering why my name got nominated. This is because every time that we're in a meeting or a committee I bring up the elderly, the geriatric perspective. I have a volunteer clinic practice in Bridgeport, Connecticut.

In my day job I'm a medical director that helps large employers with their population health strategy. But geriatrics is a passion of mine and quality is a passion of mine. I'm an NCQA surveyor. So to put it all together, they said, you know, make her stop talking, send her somewhere. I'm delighted to be here.

MEMBER SNOWDEN: Good morning, I'm Mark Snowden with the University of Washington in Seattle. There I practice clinically in a geriatric medicine primary care program where I'm the in-house geriatric psychiatrist. And then I work in nursing homes. I do research with the Health Promotion Research Center and the Healthy Aging Research Network which is sponsored by the CDC. And my current dementia work focuses on dementia and comorbid chronic conditions.

MEMBER BARTON: Good morning, I'm Mary Barton. I'm a primary care trained internist and vice president for performance measurement at the National Committee for Quality Assurance.

And we are currently working on some work with CMS on electronic measures, eMeasures, for the universe that will be using eMeasures that are related to dementia. But I'm really looking forward to this work and hope that this will be an opportunity to fill more gaps as time goes on. Thank you.

MEMBER REUBEN: I'm Dave Reuben. I am a geriatrician based at UCLA where I also lead the UCLA Alzheimer's and Dementia Care Program. It's a clinically based program, a CMMI Innovations Challenge awardee.

I also lead a grant to develop patient-centered goal-attainment scaling measures for patients with Alzheimer's disease and their caregivers. And we're developing new outcome measures hopefully.

MEMBER TENO: I'm Joan Teno. I'm a hospice physician, geriatrician and health services researcher at Brown University.

MEMBER FRISS-FEINBERG: Good morning, I'm Lynn Friss-Feinberg, senior strategic policy advisor at the AARP Public Policy Institute.

And for over two decades I worked at the non-profit Family Caregiver Alliance in San Francisco, an organization that helps families caring for loved ones with a variety of cognitive impairments including Alzheimer's.

MEMBER KAHLE-WROBLESKI: Good morning, Kris Kahle-Wrobleski. I'm with Eli Lilly & Co. I'm a research team leader in their health outcomes group supporting the Alzheimer's assets that we have. Although I'm actually here as a representative for PhRMA, our trade organization.

I'm thrilled to be here and to see the bubble charts get used. I was part of the original ADMII group with Eleanor and Katie so we've been working on this awhile. It's great to see this all coming together.

CO-CHAIR PERFETTO: And I believe we have one member of the committee that's on the phone. Susan, are you there? Can you hear us?

MEMBER COOLEY: I'm here and I can hear you.

CO-CHAIR PERFETTO: Would you introduce yourself, Susan?

MEMBER COOLEY: Yes, thank you. I'm Dr. Susan Cooley and hopefully you can hear me. I really appreciate the opportunity to participate in the meeting by phone call since I'm not able to travel so I really appreciate it. I'm physically stationed in West Palm Beach, Florida.

I am a clinical psychologist with a

background in geropsychology and I work for the Department of Veterans Affairs, the U.S. Department of Veterans Affairs where I am the chief of dementia initiative as I'm sure you knew that VA is a federal partner in the National Alzheimer's Plan. So we're involved in a variety of activities through that. And it's one of the linkages to this activity for me.

As well as the fact that VA has been working on dementia performance measurement and quality indicator development for some time also. So I'm very pleased to be able to participate in this larger group looking at these important issues. Thanks.

CO-CHAIR PERFETTO: Thank you, Susan. So I'm going to task everyone in the room with every once in awhile reminding Penny and myself that Susan is on the phone and that we need to stop and see if she has any questions or any comments. Because it's sometimes so difficult when someone's on the phone for them to get a word in. So we all have to be mindful that Susan is there.

CO-CHAIR FELDMAN: And Susan, if you need to occasionally just let out a cry --

(Laughter)

CO-CHAIR FELDMAN: -- if you're trying to say something, okay?

CO-CHAIR PERFETTO: Or send an email message that says, "I'm trying to say something and no one will let me."

(Laughter)

MEMBER COOLEY: Okay. Thanks, I appreciate that.

CO-CHAIR FELDMAN: Good. So we're going to talk just very briefly about the objectives of today's meeting.

We're all here obviously because of a deep commitment to bringing our professional expertise to bear on the issue of improving quality of identification, prevention, care, end of life for those with dementia and their family caregivers. And that's what this is all about.

We want to finalize the domains and subdomains that we've already worked on and that I think originated maybe in David's napkin documents. It's an inelegant term for that, but we seem to have adopted it.

And you obviously got the most recent round of the domains and subdomains before you arrived today.

We want to in particular we're going to spend time in small groups, identify potential measure concepts within those domains and subdomains that are areas that we think are really important opportunities and areas of development going forward.

And we're going to try not to get too bogged down into the micro micro level. But you know, sort of find that middle level of workable concepts that we can then -- where we can identify measures.

And then lastly, where we really want to end up tomorrow is with the prioritization of opportunities for performance measurement for people with dementia and their family caregivers.

And again, we asked you as homework to begin to think about some of the areas within the domains and subdomains that you already have begun to think of as highest priority.

And we're going to do this iteratively and end up ideally, and I'm confident we will, with a set of priorities that we feel really comfortable with tomorrow.

So, we've done our introductions. We've got today's morning agenda just laid out here in front of you. We're going to do a lot of sort of prep work, talk about measurement considerations, setting the stage, other projects.

We're going to have an opportunity for public comment before lunch. And then we're going to go onto our afternoon session.

And again, I don't know how well you

can see what's up there. I have to say I'm a little challenged up there too. But I have it in front of me. We're going to do small workgroup work this afternoon in generating and prioritizing measure concepts.

We're going to have a report back with hopefully lively, and knowing this group it will be lively, discussion. Once again, an opportunity for public comment.

And then we'll be adjourning. There's a dinner option for people who want this evening I'm sure. We'll hear more about that.

Tomorrow we are going to start early for those people who live in the D.C. area and end early-ish for those people who don't live in the D.C. area.

So we've got the morning packed through starting again with reviewing the prioritization work that we've done today. Again, opportunity for public comment.

And then an opportunity to discuss

additional recommendations and issues, some of which have already emerged in our prior meetings and in our email communications, and others which undoubtedly will arise tomorrow which may not be exactly the priority areas but things that we feel are really, really important and we don't want to leave this meeting without having identified them and articulated what it is that's our major concern there. So we are going to spend time for that tomorrow before lunch.

We're going to have a working lunch in which we reflect on the recommendations that have come out of the prior day and a half and on our work going forward. Once again we'll have an opportunity for public comment. So I suggest going to bed early tonight, getting up early tomorrow morning and if you're a coffee drinker acting accordingly.

So, Eleanor, I'm going to turn it over to you.

CO-CHAIR PERFETTO: So, just some

ground rules for the next couple of days. We really want everyone to actively participate.

As we've already experienced this morning please use your microphone. Be aware that only two or three of these can work at any one time so we have to all shut them off in between. So if you're not speaking make sure the light is out.

We're going to be open to sharing information, have respect for one another's views and perspectives, and try to capture as much information and come to agreement as we can.

We're going to have an opportunity for the participating audience to have some comment also. We're going to try to work to consensus. We're going to make sure that we meet the objectives that our NQF colleagues have worked so hard to get us to the goal. And they have to walk out of here tomorrow feeling like they've got what they've needed to take the project to the next step. And we're going to try to do our best to stay on time.

MS. POTTER: I want to thank you all again on behalf of the Department. This really is a Department-wide effort.

It grew out of the National Alzheimer's Project Act which was passed in 2011. The National Plan actually calls for the development of quality measures and it's why we're all here today.

There are eight different parts of the Department of Health and Human Services that are involved in this project and I'd like to welcome some special guests today.

A special guest is Deputy Assistant Secretary Linda Elam from the Office of Assistant Secretary, Disability, Aging and Long-Term Care. Linda, why don't you give a wave.

We also have Jane Tilly from the Administration of Community Living, Johnalynn Lyles from the Office of Program Integrity and

Coordination, previously with CMS and ADMII.

Rohini Khillan with the Administration of Community Living. We have Rick in the back from CMS. And if I missed anyone from the Department I apologize.

But we all thank you and the work that you do here will help the Department move forward. As we all know there's lots of holes and we can't do everything. So helping us know the priorities is important for the Department. Thanks again.

MS. FELDMAN: So, good morning, everyone. I am just going to take a couple of minutes to kind of reiterate about what this project is about and why we're here today. I feel like several of us have already kind of spoken to this already so I'll be brief.

So, as Cille mentioned HHS contracted with NQF around five topic areas with Alzheimer's disease and related dementias being one of five.

And this task actually was purposely

structured to come behind these four other tasks to purposely learn from their insights and their deliberations.

So, as I mentioned here, these other four projects, they met in early April. They had their committee meetings then. And they are drafting their reports as we speak and the public comment period on the draft reports is June 23 to July 14. So, I just wanted to call that out.

So, this specific task, as we've said we've been tasked to provide multi-stakeholder guidance on the highest priorities for measurement to improve care in outcomes to patients with dementia and their family caregivers.

One of the first steps of this project was to conduct an environmental scan of measures and measure concepts that are currently in use in the field.

As you are also well aware we have developed or refined a conceptual measurement framework that we term as the bubble diagram.

And today and tomorrow we will be working through the identification of measure concepts and prioritizing those concepts for future measure development. So, a lot to do in the next two days.

And just in terms of next steps. So we're convening today. Like the other projects after this meeting we will be drafting a report and then it will be posted on the NQF website for public comment.

That public comment will be a three-week public comment period to take place in late August through early September. We will relay those exact dates to you.

And we will also have a public webinar during that time to solicit feedback and kind of publicize what the draft recommendations are. And then the final report will be submitted to HHS on October 15 of this year.

So very briefly, we just wanted to

relay some related work that is going on both here at NQF and elsewhere.

There's several projects currently ongoing at NQF related to person- and family-centered care. The first at the top of the bubble diagram is the MAP person- and family-centered care family of measures.

So, under the Affordable Care Act HHS contracted with NQF to convene the Measure Applications Partnership and they provide pre-rulemaking recommendations on the selection of quality measures for public reporting, performance-based payment programs and other purposes.

So, this task force has been charged to identify a family of measures to promote person- and family-centered care.

Just, a definition. They've termed a "family of measures" as related available measures and measure gaps that span programs, care settings, level of analysis and population-specific topics related to the

National Quality Strategy.

Going clockwise, the green project there is another one of the prioritizing measure gaps projects. So, they have their draft report. They're drafting their draft report and it will be up for public comment as I said at the end of June.

There's also an endorsement project here at NQF related to person- and family-centered care. They are reviewing their Phase I measures which particularly are experience with care measures by the end of July 2014.

And lastly, in the purple bubble there is a Patient and Family Engagement Action Team. This is under support of HHS's Partnership for Patients Initiative.

And this is essentially a group of 20 stakeholders who have come together. They're making more action-oriented steps to focus on the Partnership for Patients Initiative, their goals of reducing readmissions and hospital-acquired infections.

So, briefly, the next bucket of work ongoing at NQF that is related to our work today and tomorrow is around population health.

NQF is developing a population health community action guide. There is a health and well-being endorsement project that is underway as well and another family of measures related to population health.

We also circulated and a colleague of ours, Elisa Munthali, will be speaking to measurement at the population health level a bit more in a few minutes. But we circulated as part of the meeting materials some background related to population health measurement.

So related to care coordination NQF has done quite a bit of work in this area. In 2006 there was a committee that identified five domains essential for future performance measurement of care coordination: healthcare home, proactive plan of care and follow-up communication, information systems and transitions and hand-offs.

In 2010 a committee identified care coordination preferred practices, 25 practices identified across these five domains.

Then there was work in 2011 to develop a pathway for care coordination measurement, specifically through the lens of health IT.

There was an endorsement project in 2012 that endorsed 12 endorsed maintenance measures.

There's a family of measures related to care coordination that the Measure Applications Partnership worked on.

Care coordination was one of the five topics for the prioritizing measure gaps work.

And there's also an endorsement maintenance project currently underway related to care coordination.

And then lastly, just some other related NQF projects that are related to this topic is that the Measure Applications Partnership has a dual eligible beneficiaries workgroup as well as a post-acute care long-term care workgroup.

In 2010 NQF developed the episode of care framework which we call out here because essentially we built off that and the ADMII work built off that. The bubble diagram is essentially -- the origination of the bubble diagram.

And then lastly, the neurology endorsement maintenance project. That was in 2013. And there were several dementia-specific measures that were reviewed during that project. So that's why we call that out here.

MEMBER TENO: You know, thinking about the environmental scan, I'm wondering one thing, whether we did this as part of the environmental scan is look for measures that are inappropriately excluding dementia from consideration for that quality measure.

And as I started thinking about this I realized that one of the largest used measures on patients' experience is hospital CAHPS survey. And none of people with dementia would ever be interviewed or have anything known about their quality of care because they don't interview proxies.

And I actually, you know, would like to either table it to discuss later. Because I actually think that if there's one thing we can do is we can make sure that the quality of patients with severe delirium or dementia in the hospital is measured. To not measure it seems just wrong.

CO-CHAIR PERFETTO: It is going into the parking lot for issues for discussion tomorrow for when we have that later session on the things that have come through this meeting. So yes, we'll definitely put that down. That's in our parking lot.

MS. JOHNSON: Thank you so much. So, from Juliet's summary you know that there's a lot going on at NQF as well as other places. I know a lot of you are involved in other kinds of projects that are thinking about dementia.

So we're trying to learn from all those but it's kind of an impossible task. There's so much there. But hopefully we can pool the things that are most important for this project.

So, going into this we thought we should go ahead and really get into the meat of what we want to do later this morning and this afternoon. Just go ahead and do a few clarifying definitions and things like that.

I think most of you are probably -- could give me lessons on these things, but just in case we'll go through very quickly on different types of measures.

Even before I do that let me mention a couple of things that I forgot to tell you earlier.

We're using these microphones and we

want you to use them for a couple of reasons, so that we can hear you in here but also the gentleman back in the corner back there just so you know is a court reporter. He is taking the transcript. So we will have transcripts of this meeting. And we make those transcripts available to the public.

So just so you know everything that you say today is on record. So I wanted to make sure you know that.

And also, we have these tent cards and they're useful for a couple of reasons. One, so we can get to know each other, but also, when we start opening up this discussion, get away from the monologue and we start actually talking amongst ourselves, what we like to do at NQF is instead of raising our hand raise your tent card. So that's how you will get our attention as we do the discussion.

So then finally we're hoping to have Chris Cassel. Many of you probably know that

Chris Cassel, a geriatrician who has been working in the quality field for many years now is our CEO. She's been here just under a year now. And she was looking forward to being at our meeting and saying some introductory words and unfortunately caught an earlier plane than we thought. So she's in the air right now. She's not going to be able to address us.

But she did want to say hello. So hello from Chris. And just wanted to reiterate how much personally she thinks this work is important and wanted you to know just how much she appreciated your help in this work.

So, now for the technicalities here. Clarifying the term "measure." That one, at NQF we have a little bit different definition sometimes than people out in the field.

So when we talk about a measure generally we are talking about measures of providers or organizations. So, you can have patient-level measures, or measures such as a blood pressure, or lab score, or information from a survey like the CAHPS or something like that. Those are patient-level measures.

And I think where we have to be careful in what we're doing in this project is if you're thinking about like the CAHPS survey or the CES depression scale, things like that, we also use that term for a measure. We call those things measures sometimes. So we just want to make sure that everybody is on the same page.

What we're looking for in this project is the performance measure. So that would be information that is aggregated up from the patient-level information and used to look at performance and quality and that sort of thing among different providers.

And that provider might be an individual clinician, it could be a facility, a home care agency, an ACO, all kinds of different levels of aggregation there. So, I wanted to make sure that we were all comfortable with the term "measure."

So, measures. Measures are used for quantifying performance of the healthcare system. And the reason that we are interested in measurement of course is because measurement we think drives improvement. They inform stakeholders and they also as we know well influence payment.

But they are not the end in and of themselves. So, but we need good measures to be able to do all of these things.

So, the goal of measurement is really to improve care for the patient. So we want to keep in mind that our ultimate customer is the patient.

And I think it's probably fair to say too that we are all ultimate customers at some point in our lives, either with our families or at some point ourselves. So, this is very important to all of us.

There are lots of different types of

performance measures. So we generally, we're probably most familiar with quality measures. And in quality measures there's lots of different types of those as well.

So we have outcome measures, and those can be things like -- basically they are the results of care. So, sometimes outcome measures could be things like fall rates, those kind of things. Or a lot of times we think about mortality rates. That's an outcome. Sometimes we look at readmission rates and we think of those as proxy outcome measures.

We also have other kinds of what we call patient-reported outcomes. So those are things that come directly from the patient or from the person who has experienced care. And those are a little bit more complex in some ways than the typical outcome measures.

And we also have intermediate clinical outcome measures. Those are things like blood pressure rates, percentage of patients that are in controlled HbA1c, for example. Those kind of things are intermediate clinical outcomes.

We have process measures. Those are measures that measure whether some action that we think is useful actually is being done.

And then we have structural measures. Those reflect the conditions under which provision of care is done. It reflects the infrastructure of our healthcare system.

So those are the different types of measures that we are used to thinking about in terms of quality.

There are also resource use and cost measures that we use. And if you combine, and I'm not sure this is really being done yet but we're working towards it, combining resource use and quality measures equals an efficiency measure. So that's where we as a country are trying to go.

There are some other kind of fancier kinds of measures. We talk about composite measures. Now, a composite measure is really just a combination of other types of measures. And it could be a combination of outcomes, or a combination of process measures, or a combination of any of the above in any kind of way.

We have population health measures. And those are tricky and that's why we've asked Lisa to come and talk about those for us. I even asked her is a population health measure a type of measure and she said well, it is and it isn't.

So we'll let Lisa walk us through population health measures which are a little bit different in thinking. We have to kind of think about those a little bit differently maybe than what we're used to.

So at NQF -- just so you know, NQF in general we are the endorser of measures. And I'm going to get into this just a very little bit in case you're not familiar with NQF.

But we do have criteria that we use

to evaluate measures if somebody brings in a measure and wants it endorsed.

But we actually have a preference for outcome measures. And really outcome measures, you know, the preference is there because outcomes are really what patients are interested in, right? As a patient I'm not that interested in the process measure or the structure measure. I want to know am I going to have to go back to the hospital, you know, or am I going to die?

But there is a need for all of these different kinds of measures. And so we prefer outcome measures. And then after that intermediate clinical outcome measures.

And what we are looking for really are those measures that have the best evidence that we know can -- by measuring those things we can actually improve quality. So that's what we're looking for.

Process measures, structural measures, some of those -- can you go to the next slide? I think we show this a little bit in the next slide. Yes.

What we're interested in at NQF preferably are measures that are what we call proximal to desired outcomes. So, in this example we have an outcome measure and several different structure and process measures.

And you can see that all of these things on that table is important to do. You have to have the right organization policies and procedures.

This one actually comes from a PROM. We probably should have used a little bit different slide here. But basically what this is trying to show is that some processes and even some structures are closer to desired outcomes than others. And that's where evidence comes in.

So, if you're thinking about assessing somebody and then figuring out a diagnosis, and then finding a treatment, and applying that treatment, and then seeing if the outcome is what you are hoping based on that treatment, there's places for measurement in all those different steps of the care process.

So, again, NQF prefers the ones that are closer to the outcome, but we also know that the other types of measures are important.

MEMBER COOLEY: This is Susan. The slides are not showing on the web streaming.

MS. JOHNSON: Okay. What are you seeing, Susan?

MEMBER COOLEY: Just the slide that had project next steps. It didn't advance beyond that. I'm going to log out and log back in and see if it is advancing but I needed to refresh somehow which I don't have an option to do. So I'm just going to log out.

It did not go past project next steps. It has 13 in the bottom right corner.

MS. JOHNSON: Thank you, Susan.

MS. FELDMAN: I'll email with you, Susan. This is Juliet. And we can troubleshoot.

MEMBER COOLEY: Okay. Sorry to interrupt.

MS. JOHNSON: That's fine. So we're going to back to the PRO, PROM and PRO-PM discussion. You guys have seen this from us a couple of times now.

And again, it's mainly because of it's real easy to get tripped up on terminology.

So again, this is just to remind you that in NQF-speak, and I think it's becoming more not just in NQF, but it's becoming a little bit more out in the world we talk about PRO-PMs, those are patient-reported outcome performance measures.

So basically the PRO would be a patient-reported outcome, for example, depression. And you usually would use some kind of instrument or scale, something like that to figure out if somebody has symptoms of depression. So that would be the PROM, the patient-reported outcome measure.

And then from those kinds of instruments or scales you could construct lots of different kinds of performance measures. And those are the PRO-PMs.

So again, we may not have to refer to this too much but just in case we wanted to put this in front of you.

Levels of analysis. So basically this is the term that we use when we're talking about who is being held accountable in a measure.

So, you can measure an individual clinician or provider of some sort. Doesn't have to be a doc of course. You could think about measuring groups of physicians, or other providers.

You could think about facility-level measures. And again, that would be, it could be a hospital, it could be a home health agency, a hospice agency, something like that.

You could go up to the health plan level. Go up even further to something like an ACO.

And then finally, you could go all the way up if you will to population-level measurement. And that could be things like community. And I will say that in air quotes because "community" -- different people have different definitions of what a community is. But oftentimes we think of population-based measurement at a state level, for example, or sometimes national.

So, as we think about later today and particularly tomorrow morning we want to think about levels of analysis. And as you're giving advice to HHS about a pathway forward for measurement what would be the level of analysis that would be appropriate for some of these measurement concepts that you're putting forward.

I mentioned very briefly that NQF

endorses measures. And this is just a very quick slide showing you what our major endorsement criteria are. There are five of them.

The first is importance to measure and report. So, the goal is to measure those aspects with the greatest potential for driving improvements.

And these are in a hierarchical format here because we feel like if a measure is not important for measurement and reporting then it really doesn't matter so much if it's scientifically acceptable or feasible, that sort of thing.

Under importance to measure and report we look at evidence, we look at what we call performance gap or opportunity for improvement and then we also look at priority. Does it hit a high priority aspect of care?

Scientific acceptability. What we want is to make valid conclusions about quality so we need measurement that gives us both reliable and valid results.

And those first two are what we call must-pass criteria. So, measures that come forward to NQF must pass these two in order to be endorsed.

We also -- this is a little bit out of order here. We also look at feasibility. We want to have measures that are feasible to implement. And the goal there is to have as little burden as possible for those who are implementing the measures.

And then we also want usable measures, or it's really usability and use. And the goal is to have measures that are out there that are in use and that have been shown to drive improvement.

And it's under that criteria that we also look at things like unintended consequences. Sometimes as you know there can be unintended consequences. We at NQF want to make sure that we keep an eye on that and make sure that that's not happening to the best of our knowledge.

Finally, we have comparison to related and competing measures. So, that one is -- that one's a little bit hard to do sometimes. But the idea behind that criterion is we don't want to have thousands of measures out there that are doing very similar but not exactly the same kinds of things because it just creates confusion. So we ask that if measures are basically measuring the same thing we try to have just one of those instead of two or three. Sometimes there are reasons and justifications for having more than one.

And then sometimes measures are similar. For example, we may have a lot of diabetes measures that are measuring different things that maybe the population is always a diabetic patient. So it makes sense to try as much as possible to define a diabetic patient in the same way across measures. And that's what we mean by comparison of related measures. So that's some of the stuff that

NQF tries to do.

Now, the reason that I brought this to your attention. We will have a little bit of discussion a little bit further down the road about quality improvement and accountability.

So right now NQF, when we endorse measures, the measures that NQF endorses are meant to be used for both of those purposes.

And by accountability purposes that can be all kinds of different things such as accreditation, certification, public reporting, payment, all kinds of different things for accountability.

So, when we talk about an NQF-endorsed measure we think about being able to do internal quality improvement as well as doing some of these -- having useful measures for these accountability purposes.

So one of the things that we have to talk about at some point later today and tomorrow is when you put forward measures, your prioritized list, we are not necessarily saying that things have to be ready for NQF endorsement. Because maybe we're not quite there yet in terms of the science. And that's okay.

But I think it's a question that we need to talk about. And so I want to make sure that you know that if we're talking about NQF endorsement it's both of those things, accountability and QI.

So, the next piece is going to be about population health measures. And as I said, this is not my area of expertise at all so I've asked Elisa Munthali who leads a lot of our population health work to come and give us a little primer about population health measures.

When we finish this little soliloquy from Elisa and I we'll open up the floor and we'll start talking about the challenges that we're going to be facing with measurement. And some of the things that we want to get on the table before we delve into the real meat of our day. So, Elisa.

MS. MUNTHALI: Thank you, Karen, and good morning, everyone. My name is Elisa Munthali. I'm the managing director for our performance measurement department here.

And as Karen mentioned I lead a lot of the population health work including our current work around health and well-being population health measures.

And so I just wanted to give you an overview of what that portfolio looks like and how we came about bringing these groups of measures together.

And so the evolution of the population health portfolio at NQF is informed largely by the National Quality Strategy which includes making sure that there's better care, affordable care and that populations are healthy, and the people within those populations are healthy.

Specifically, we're focusing on the

long-term goals of working with communities. And that includes the provision of not just clinical preventive service measures but also those measures that promote healthy living and healthy lifestyles, and those that speak to the socioeconomic and environmental determinants of health.

Our portfolio is also informed by our previous work. And our first project that was focused on the endorsement of population health performance measures was in 2011.

And because it was our first project we conducted significant foundational work which included review by a multi-stakeholder committee similar to this committee that looked at our measure evaluation criteria. So the criteria that Karen just spoke to you about.

And they wanted to know whether those criteria were applicable to population health measures. And by and large they decided that, yes, these should be applicable to population health measures, but we may need to change some of the clinical terminology and nomenclature included in there.

So what they did is develop guidance and context, additional context to help measure developers that were wishing to submit population-level measures to NQF.

In addition to that foundational work we commissioned Dawn Jacobson at the Public Health Institute and at Steve Teutsch at the L.A. County Department of Public Health to help us write a background paper on population health.

And the paper was to include an environmental scan of community and population-level measures and definitions for population health and related terminology.

In the paper Dawn and Steve did identify several definitions for population health but none that was universally accepted.

So, the committee landed on two very

important definitions that I did want to share with you.

The first is what we're calling population health. We also refer to it as total population. And this includes all individuals in a specified geopolitical area.

Another related terminology which we spoke to earlier when Karen mentioned this confusion around communities, to alleviate that confusion they came up with a term that we call subpopulation. And that includes a group of individuals that are a smaller part of a population.

The subpopulations can be defined by geographical proximity, age, race, ethnicity, occupation, schools, health conditions, common interests, or any number of other characteristics.

As I mentioned before, there were many things that Steve and Dawn went out there to look for us as we began this foundational work. And one of them was really giving us guidance on how to measure and assess population health, the determinants of health and improvement activities.

They also suggested that when we're looking at putting together a portfolio of measures we look at an integrated measure framework that includes not just total population but those measures that matter around determinants of health and improvement activities.

One of the things that Steve and Dawn also did was to emphasize the importance of aligning the clinical care delivery system's initiatives around population health with the public health system.

And they also outlined methodological challenges of population health measurement including timeliness of data, availability of data and the like.

So, in the end we had a two-phased project as part of this inaugural project and we endorsed 19 clinical preventative services measures. So those speak to the National Quality Strategy's emphasis on the clinical preventative services. And it included immunization measures as well.

The second phase included just five endorsed measures around healthy lifestyle behaviors and broader population health measures. And this was despite really targeted outreach to measure developers.

We learned from talking to measure developers through this process that many of them had difficulty submitting through the NQF evaluation process. Part of it was they didn't have the resources to do the testing required for submission.

And so the Committee also identified some gap areas. And some of those were around those upstream determinants of health. We do have some in our portfolio but not enough.

They also identified measures that assess the physical environment like air pollution, built environments and clean water.

They want to also see patient and population outcome measures that were related to improvements in functional status. And they wanted more emphasis on measures that focus on subpopulations like the disabled and elderly populations.

And so I think this is included in your materials. This was part of the measurement framework that Steve Teutsch and Dawn Jacobson recommended to us.

It includes the concept of total population with related domains and some examples of what kinds of measures and indicators one could develop.

It also includes the determinants of health and the health improvement activities.

And so, as I mentioned earlier, the work that has preceded us with the National Quality Strategy and also our previous work with the -- leading with the foundational paper from Teutsch and Jacobson led to what we have in front of us.

And this is really the NQF -- a snapshot of the NQF portfolio. It includes the domains and subtopics. The majority of our measures are at the top. It's the third column, primary prevention and/or screening. We have about 25 measures in that domain, followed by some measures in the social determinants bucket which is the last column. There are about 17 measures. And the least are those that are related to health-related behaviors.

Not all of the measures are included in the health and well-being project. Some are cross projects and those I've highlighted at the bottom like the osteoporosis screening. That is assigned to our endocrine project. And the HIV and tuberculosis screening which is assigned to our infectious disease project.

And so what I've done in the next slide is just kind of pull out one of those measures that is in the domain of a community-level indicator of health and disease.

This is a population-based measure. It assesses adult parent smoking. It was submitted by the CDC.

And for a description, it's the percentage of adults that are 18 and older in the U.S. that are current smokers. The numerator is the current adult smoking population 18 and older. And the denominator are all adults 18 and older who live in the household.

And this is survey-based. It actually had initially been submitted to the NQF from the National Household Interview Survey.

Our committee had several issues with that because that survey is assessed at the national level. And they really were concerned about that locus of accountability at something that was that high up and couldn't be drilled down.

And so we did extensive technical assistance and worked with the developer to change the measure using another survey tool that could be assessed at the state level. And that was the BRFSS, Behavior Risk Factor Surveillance Survey. And so with that they felt a lot more comfortable with this measure that was able to drill up and drill down.

And I think that's it for me.

MS. JOHNSON: Thank you, Elisa. And I really wanted Elisa to give you that background on population health because I think a lot of times we're used to thinking about measurement and developing measures at these levels of accountability that are at the clinician level or maybe a facility-level.

And the population health measures are a little bit harder to think about, but maybe that's something that we want to think about for dementia. Maybe it's not. You guys are going to help us talk about that. But, again, just to put that on the table.

So, there's a lot of measurement challenges, right, about measuring for quality of care for the dementia population. And we've put a few of these on some slides. And I'll just go through them very quickly.

Dementia is aggressively debilitating and ultimately terminal. Care is provided across settings within and without -- outside of the healthcare system.

There are, as we have already discussed, issues with detection and diagnosis.

We need measures for both the person with dementia as well as their caregiver and family. As Joan has mentioned, we need to think about being able to get proxy responses from the family or caregiver because at some point the person with dementia may no longer be able to respond.

Then there's the problem what happens if there's not a caregiver for that person?

As I mentioned before NQF is really interested in measurement that has a strong evidence base. But we may not have a strong evidence base for things like prevention and treatment and screening, things like that. Maybe the science hasn't quite caught up to us yet. So that's another challenge as we think about prioritizing things.

And then finally it kind of goes back to that one slide where I showed you lots of different structures and processes and outcomes. There's a lot of important things to do but maybe not all of them need a quality measure around them.

So, those are some of the things that we had thought of and we've talked about in the past.

So, as we go through the next about 20 minutes or so what I want to do is open up the floor for you guys to talk about other challenges that we may want to get on the table as well as considerations for prioritization.

So, what would be really great is if we had a list of things for you to use to prioritize, right? We don't quite have that list. But things that we might be thinking of are accountability versus QI, the types of measures. By that I mean the structural process outcome. The levels of analysis, et cetera.

So, let's see. Is there another one or is that my last one? Yes.

Other potential considerations that you might use as you're going through this mental exercise of how do you pick the things that you think are the most important for our next measure development.

Evidence, having a broad population, how feasible is it. We know we can do short- and long-term types of things. Some things we can probably do now. Others may have to wait five or ten years for the science to catch up.

We have certain high-risk populations that we need to be sure that we don't leave out. There's lots of creative and novel approaches for doing measurement. We talked about, real quickly, the PRO-PMs and the composite measures but I'm sure there are others.

And then the idea of parsimony. We don't need a thousand measures, right? What can we do to have the fewest measures possible to get the most bang for our buck, if you will.

So, let's open it up for some discussion.

CO-CHAIR PERFETTO: Karen, before we do that I just want to stop for a second. A lot of information was presented that's background information. And so before we go to the next step to have this discussion, are there any questions on what was presented for Karen or Elisa? Lynn?

MEMBER FRISS-FEINBERG: The background information was very helpful. Thank you for that overview.

I was struck by the fact that we know that person- and family-centered care is a priority for the National Quality Forum. And yet within the slides even sometimes within some of the columns the word "person" was used and then "patient" was used.

So it's just a comment and I just wanted to say wouldn't it be wonderful if the National Quality Forum would lead the way in consistently using person- and family-centered care.

CO-CHAIR PERFETTO: The slides are reflective of the schizophrenia on this issue that we see all over the place, that's true.

Any other questions or comments before we go into a discussion period?

So Karen's question to us is when we're thinking about our measure prioritization, which we're going to spend the rest of the day on, what are some of the other things that we need to consider?

She's thrown some out here that are on the slides that she just reviewed. But is there anything that we're missing, or anything that's here but needs to be elaborated on in any fashion?

MEMBER REUBEN: Yes, I'd like to kind of open this up in terms of a different challenge. And it's really about the conceptualization of quality measurement, particularly with respect to outcomes in dementia care.

So, as I tell my students and residents, you've seen one patient with Alzheimer's disease, you've seen one patient with Alzheimer's disease.

And in fact the whole concept of measuring quality of care assumes that everyone has the same desired outcomes. And in fact, in dementia, it's very, very different.

So, for example, you would say gee, for us around this table going to a nursing home would be a very bad outcome. But for some patients with Alzheimer's disease it turns out that's the best outcome for them.

And in fact, maybe conceptualizing this rather than here's a set of measures and we'll see how people rate on these. Maybe the measures should be individualized.

This is a different construct. This doesn't happen now. You say gee, these are the measures that are important to me, me being the person, me being the family and the caregivers. I don't care about the other ones. I don't care about -- this is my set of measures and this is what counts to me.

That involves a different way of thinking about developing measures. It's not a blanket universal set of measures. It's a set of measures that people can choose from and say these are the ones that are important to me.

I think that -- if we ignore that then we're doing same old, same old, and we're not doing a service for our patients.

CO-CHAIR PERFETTO: Karen, could you comment on that? Has NQF dealt with that before in the past for other areas that it's done work on where there's been any thought to an individualized measurement approach?

MS. JOHNSON: I think so far-- I think people agree with you, David. I don't know that we've gotten very far with that.

And the problem, I think, is the accountability piece. Because what we're interested in is improving care for the patient. So you want the patient to have that list. But the accountability is oftentimes at the clinician level or whatever.

So I don't think we've had much success so far in constructing measures that are -- that have that individualized piece to it to a large extent.

Now, I think, and Eleanor, you could talk to this. For -- when NQF did some work and Eleanor was on the panel on the patient-reported outcomes, one of the first questions in that pathway of going was is this, this thing that you're thinking about measuring, is that actually important to the patient? So, from that perspective I think it is.

And maybe, Eleanor, you might want to elaborate on that one if you can?

CO-CHAIR PERFETTO: Well, it's a general rule that when you're developing a patient-reported outcome measure, a PROM, that you would begin with the patients and interviewing those patients and determining the concept that would come from those patients.

And so you wouldn't even get to the point of developing a measure unless you'd had that conversation and done that background work first, get those concepts from the patient population, from the caregiver population, and then go the step into developing the PROM, and then as that group was assigned the task of talking about how you take a PROM to become a PRO performance measure.

And so the idea is it began with the

patients in the first place so you should be capturing those concepts.

I think you're thinking about taking that to the next step where if you had five concepts that you turned into measures some patients may pick number one, others may pick number three. And I think we're not there yet.

But it is something that we're going to put on our list of how we think about integrating that kind of thinking into -- we can put it on our parking lot list tomorrow.

CO-CHAIR FELDMAN: So, first of all it's hard for me to believe that the person- and family-centered outcomes group couldn't have been grappling with this issue.

But it seems to me that it leads back to some very complicated aggregation of individual process and outcome goals where you, you know, you sort of identify what the person's preferred outcome is through a process and then you link it up to the desired outcome. And then you try to aggregate it up.

And I think one of the challenges we're going to have is that it's not been done, or it's certainly not been done to the level of satisfaction that would meet an NQF threshold.

And then how do we encourage that kind of work to be done. Maybe that's something for PCORI or whatever, the Patient-Centered Outcomes Research Institute.

But I think it's a huge challenge. And a big policy issue because I've done a little work with managed care plans that are now becoming FIDAs and FIDA is the integrated plans for Medicare and Medicaid dually eligible people where there's a huge emphasis on a person-centered plan of care.

And yet the outcome measures to which these plans are held accountable don't reflect that at all.

So I think it's a huge issue. And maybe one of our recommendations of some kind going forward could be to direct more work in this area. It seems rather inadequate to what we're grappling with.

MEMBER SNOWDEN: I think the other challenge is most of the people that I see and treat with dementia don't just have dementia.

And so keeping in mind that this is potentially one of a number of conditions and depending on the outcome and the goal some of those other conditions may be bigger drivers of what we are concerned about than the dementia itself.

MEMBER KAHLE-WROBLESKI: Yes, I think one of the other places too for us to consider where I think there is going to be difficulty is, and apparently my memory is not good enough to go three slides back.

But the concept of patients with dementia being treated not just in a medical setting but also in a social care setting. And so how to integrate these outcome measures, how to think about if we are thinking about quality indicators more for the medical system which ones can we really hold the medical care system accountable for? How should they be responsible?

Part of it is around their personalized outcomes, right? Some of them may be more focused on managing medical issues, being part of that system, but other people may prefer to be out of that system.

And so how do we make sure that if we're putting something in place that's appropriate to the provider or to the healthcare system that we're going to be focusing on and not losing those persons who may choose to be out of the healthcare system in some instances.

CO-CHAIR PERFETTO: Good points. Katie, you were next.

MEMBER MASLOW: I don't want to take away from what Chris said, but thinking about what Dave raised, it seems to me that for people with dementia something that is generally not happening now and would be a big plus is a structured care planning process.

So we're talking about a process. But that process could -- it doesn't get to where you want, but it could be defined as involving -- that the person and the family have goals, that the care plan is based on their goals.

And of course there's a lot of good work that's been done about that setting of goals in dementia. Carol Whitlatch's work and Lynn has also worked on this.

So it seems to me that -- I know I had suggested this earlier but it seems to me that care planning might be a -- is it domains that go across? What goes across?

MS. JOHNSON: Subdomains go across.

MEMBER MASLOW: Subdomains.

MS. JOHNSON: Yes.

MEMBER MASLOW: It might be a subdomain because it's so lacking and so important. I think that it's not really --

there's not enough attention to it.

I don't know if that's even close to what you're thinking of.

MEMBER REUBEN: I think this -- you assembled a lot of really bright people who understand this disease or this group of diseases. And to say, you know, reduce nursing home placement, or number or percentage of people who survive a certain amount of time is really short-changing the field.

And you know, even though this is going to be hard, even though this is new ground we shouldn't run away. We should really try to face that challenge of identifying personalized measures.

And there has been some work on goal attainment scaling in dementia. It's pretty primitive but it is there. And perhaps we can really try to push that further.

MS. JOHNSON: And just to make sure, you probably saw it in some of those premeeting materials that we made available in some of the other task 5 work we do have a person- and family-centered care group. And they've grappled with this. And they've made some recommendations.

And the care coordination group which was looking at the primary care to the community, they have also made some recommendations.

So there are recommendations coming out of groups like you for development. And Mary may even be able to talk about developers a lot of times will have patients on their panels when you're thinking about measure development. So I think there's some of that.

But I don't know that many of those kind of things have come into NQF so far.

CO-CHAIR PERFETTO: Cyndy?

MEMBER CORDELL: I just want to say that one thing that should be a bullet is this is a disease that has no treatment to stop its progression or cure it, and that's one of our issues on why it's so difficult to get a typical outcome measure that we're used to seeing.

MEMBER TANGALOS: One of our homework readings was to look at the National Plan. And that will put you to sleep real fast. It is exceptionally long. It is I think our framework for all of this from ESPE.

And I really don't think we should get too far away from the National Plan. I mean, there was so much work put into that by so many people that everything that we come up with in terms of our measures ought to harmonize, ought to have a reference to and ought to be a part of that National Plan.

CO-CHAIR PERFETTO: Thank you. And I think harmonization is something that's very high on the priority list for NQF so I think that's a good point.

MEMBER HASHMI: I'll second what Cyndy said. This is a difficult condition. I was trying to come up with an analogous clinical condition or a social condition.

Because this one borders not just clinical and the biological model, but it is much more so a social issue as well. And success, as David said, starts with the individual-level metrics.

But again, as a society, we need to be heading in that direction. We need to have measures that tell us that, you know, in the organized healthcare system or organized social system or community support system that we are making progress.

And so we need to think about the metrics almost in a social construct, not just in a disease construct.

MEMBER JANICKI: I was going to try to mirror some of the things that have been said.

But also as looking at the documents you sent up one of the things that struck me is that there's not a foundational differentiation of what Alzheimer's and related dementias is in relation to other public health medical issues.

And I think we're struggling with that. I think the document somewhat struggles with that. Because you need to identify I think the key factors that differentiate this group of individuals, large group of individuals who are affected. And it quite well articulated the National Plan by the way.

And go from that point in terms of defining what is it that you want to do in terms of measurements, what is it you want to do in terms of defining quality factors. Because of the nature of the disease and how it affects people. What are all the accoutrements that circulate around that disease.

In addition, for the various populations that are affected by it, you know, and differentiation points.

I think maybe a starting point is really to say, okay, what is it about dementia and its related conditions that really differentiates it somewhat from other factors and then how do we address those measurements.

MEMBER TENO: So, this is going to get messy really quick. And so one big problem is the denominator. There's no easy way to get the denominator.

Just look at the work that Susan Mitchell did on death certificates. Even in a cohort of patients that she identified as having moderate to severe dementia in looking at whether dementia was reported on the death certificate it was undercounted by something like 20 or 25 percent.

So, how you get the denominator is going to be critical for each population. And you're going to have to solve that problem with each population.

Second of all, it's going to get messy really quick. And perfection can be the enemy of the good.

And the example I'll give you is the

MDS 3.0 quality measure. The MDS 3.0 quality measure for long-term care patients only reports on people who are able to report. Which means that you're excluding those people with severe dementia.

Now, I can guarantee you, I've taken care of those patients for nearly 30 years, they still have pain. But you have to rely on the staff's ability to make a judgment on what that level of pain is and initiate a care plan.

Part of the problem is there's not going to be a measurement that you can rely on. You know, we've set this gold standard where we want something that is a scale that's reproducible. All the non-verbal scales for pain have not shown a good relationship to severity. So we have to rely on a staff at the bedside to make an assessment of the severity of the pain that initiates a treatment plan.

Well, that means when you start

treating measures you're going to have some people self-reporting, you're going to have some people you either exclude from the denominator or you rely on the staff to make a judgment on the pain. It's going to end up with a messy measure.

But excluding this population I think is far more dangerous. It means that they're undercounted. It's not part of your quality program. No one's going to pay attention to pain in people who can't meet the specified measure.

So, and then I think the other thing you have to think very carefully is time frames on when do you do certain things under what task.

So, for example, when do you have a long advanced care planning discussion with that family member? There needs to be a trigger that gets people into that denominator.

So I wouldn't underestimate that

there's got to be a lot of measurement work done and there's got to be some decisions made on how messy you want the measure to be.

Otherwise, you know, I think we've gone for perfection of not having messy measures which means we're excluding a sizeable portion of people from the denominator. And that's really concerning to me.

And I think we're going to have to be willing to talk to family members who are really at the bedside. You know, I think we've discounted family's role in providing care and coordinating care.

I've been doing focus groups now for almost 20 years and the number one thing that families talk about is their difficulty with the healthcare system in terms of advocacy and care coordination.

CO-CHAIR PERFETTO: All good points. Thank you. Any others?

MS. JOHNSON: Okay, I think we got

some great input. So this is great.

We are going to have in a couple of different places throughout the morning here we're going to have a couple of parking lot flip charts that as things come to you throughout the day feel free to write on the parking lot.

And we'll try to get to them, the different things, either tomorrow, this afternoon, or as we write up the report.

We are going to be writing a report. You've probably seen our draft that we had, but the final report will try to verbalize a lot of what you guys are talking about. So, just anything you want to tell us to get in that report we will try to get that too.

So, we're actually I think pretty much on time. And I think it's time for a break. So we're going to take a 15-minute break. Help yourself to more breakfast.

(Whereupon, the foregoing matter went off the record at 10:57 a.m. and resumed at

11:17 a.m.)

CO-CHAIR PERFETTO: Okay, we're ready to get started. So if you take a look at your agenda you'll see that we have a session lined up here that's called Setting the Stage for Quality Measurement Opportunities.

And we're going to take a minute to review the framework just to put it in front of everyone. Everyone here has had an opportunity to comment on this framework so we're going to put it in front of you and we're going to just work to clarify definitions if we need to.

And then we want to use this as a discussion for moving into some quality opportunities. And we're going to have some people who are around this table who have submitted some vignettes actually talk about those vignettes to kind of put in our mind what are some of the issues that we're thinking about when we're thinking about what is a quality opportunity.

So we've had some vignettes that have been put forward. We're going to go around the room and have people talk about those.

But the first is that we -- this is our new and vastly improved bubble diagram that everyone has really given a lot of thought to. And we really appreciate all of the thinking and discussion that's gone on around this.

I think, Chris, it's changed since a year and a half, two years ago, and I think it is vastly improved.

But is there anything that -- Karen, did you want to raise anything on this now or say anything about this diagram before we move on?

MS. JOHNSON: Not really. I think this is pretty much what you guys are used to seeing.

CO-CHAIR PERFETTO: This is what we came up with.

MS. JOHNSON: This is what we came up

with.

There are I guess one question still open. Do we need -- and Katie has already alluded to this. Are there still a few more subdomains that we need to add? And we've got a couple of those in the feedback that came through. So I think that will come out more in our discussion this afternoon when we talk about concepts and things like that.

CO-CHAIR PERFETTO: So keep this framework in mind as we work through the rest of today and tomorrow.

We think it's pretty solid right now because everyone here has had an opportunity to really beat up on it. But that doesn't mean that by our last session tomorrow we may want to come back to this and revisit again to say oh, wait a minute, there's something really important that we talked about sometime in the next day that needs to either go on here or be rearranged in some way. So this is at the forefront of our thinking as we work through this.

And as much as we're happy with it now, it's never completely set in stone. And we can have a short discussion tomorrow when we return to it to think about anything else that needs to be tweaked. Barbara?

MEMBER BAYLIS: I notice that on the model, top line, it has four things. It says quality of life. And then the bottom line, it also says quality of life. So, as we go through this I hope I get some clarity of why it's there twice.

CO-CHAIR PERFETTO: I think the only thing that I would point out is that when we were looking at these trajectories, what we're calling the trajectories, one was keeping the caregiver in mind and one was keeping the actual person with dementia in mind. And so quality of life on both sides. Is that the one you're seeing?

MEMBER BAYLIS: When you say it, it makes sense to me but I don't see it in the model, that one part is -- oh, that's so light. Okay, caregiver, thank you.

(Laughter)

MEMBER BAYLIS: And the person with dementia. It didn't stand out, didn't pop out.

CO-CHAIR PERFETTO: We'll make it pop.

MEMBER BAYLIS: Okay.

MEMBER TENO: One thing to think about is this looks like a time-line. And the question is are the bubbles really in relationship to the time-line of the interactions with the healthcare system?

It seems to me that mild, moderate and severe gets very compressed. And you might want to think about, you know, how mild dementia actually is probably there prior to that.

And also think about how you're representing this within the time-line. Half the time is not spent in the evaluative phase.

You know, if anything once you have someone who's diagnosed with dementia you're talking about something that runs an 8- to 12-year course.

CO-CHAIR PERFETTO: We're not really to scale is what you're saying. Yes.

And I think our little tails were intended to show that things probably happened long before. But maybe we need to rethink the scale of some of this. Okay.

MEMBER JANICKI: I was just going to say in your -- going kind of along with this time-line issue and the structure division of this where you've got the little dots that went from left to right and you have sort of cognitive symptoms and you have diagnosis of dementia.

What's kind of missing in the right side is something like course of decline, or course of condition. Just something that kind of, you know, breaks that -- identifies that other --

CO-CHAIR PERFETTO: Okay. That it's gone to a different phase.

MEMBER JANICKI: Yes. Because you're missing something that -- after diagnosis you've got something that's missing.

CO-CHAIR PERFETTO: Very good. Lynn?

MEMBER FRISS-FEINBERG: Just in looking at this again we have experience of care under the person with dementia but not under the family caregiver. And we might want to consider, I hope we would, putting it up on top as well.

MS. JOHNSON: Yes, I actually had that down and we possibly would want engagement up there as well.

CO-CHAIR PERFETTO: Maybe all of them.

MS. JOHNSON: Yes. And I think the other thing that's a little tricky is in some cases we have the bottom trajectory is the person with dementia.

But we'll also keep in mind that

sometimes we would be asking the person with dementia things. And sometimes we would be asking the caregiver as a proxy about things.

So both of those things are in that bottom trajectory whereas the top trajectory is about more the experience of the caregiver. So I hope that makes sense but if it doesn't we need to maybe sharpen it just a little bit.

CO-CHAIR PERFETTO: Yes, yes, okay.

MEMBER JANICKI: If I may, just one other thought. The last bubble on the right you have end of life and you have bereavement. A couple of things.

One is obviously, bereavement is important. But if you're dealing with a long-term illness it's not like a short-term death where someone is really affected by it. You have time to worry this whole thing out. So, I don't know whether bereavement really needs that level of focus here.

But the second point really has more to do with maybe family counseling. You're dealing with a course of a disease that oftentimes may have people raise issues in their own minds, other family members, whether that's going to be in their genetic structure or not.

And maybe something that recognizes that concept of providing some kind of counseling to families around implications of other people in the family network on the disease might be useful to have.

CO-CHAIR PERFETTO: That's good. That's something that has not been raised before so I think that's something that we need to think about how it gets incorporated in. Yes.

MEMBER BARTON: I was just concerned that across the caregiver trajectory it looks like those things are also on a temporal scale. Or you know, possibly you would consider the education comes first and then these other things are following.

But then in the person with dementia

trajectory -- the word "trajectory" implies that you're trying to go from A to Z. And those things are kind of all coexisting, all important all at the same time.

CO-CHAIR PERFETTO: Sorry, we have a small disaster happening that's being dealt with.

I think that these subdomains that are going across, those were not intended to be a trajectory. But I think if we're conveying that then I think we have to do something about that, yes.

Because I think the intent was just to try to capture them all and to keep this concise they got put in a row. But I don't think that they were intended. I think they were intended to be, that they are components of the trajectory but not necessarily happening sequentially. So we'll have to figure out a way to convey that better.

I think they used to be listed in a column and it got too big for the paper.

(Off mic comment.)

MS. JOHNSON: Can you repeat that?

MEMBER HASHMI: My suggestion was let's take the word "trajectory" out of there, call it "caregiver experience." And then list them however because they're no longer linear.

CO-CHAIR PERFETTO: And we can do the same with person with dementia experience instead of trajectory and that might help clarify all that. Okay, very good. David?

MEMBER REUBEN: I think those are both great ideas.

I would -- picking up on Barbara's confusion here with this is I would take the caregiver whatever it is, that line up there, and put it underneath the patient -- the person with it.

And that way you'd have person and then you'd have caregiver right on top of each other. And then you could line up the ones that are similar and see. At one instance you can see what's similar and what's different for the caregiver and for the person.

And then you'd move the bubbles up to the top which kind of makes sense anyhow.

CO-CHAIR PERFETTO: Bubbling to the top. Got it.

(Laughter)

MEMBER REUBEN: Yes, it would be the bubbles and it would be the patient or person, and then it would be the caregiver, and then NQF or National Quality Strategy.

CO-CHAIR PERFETTO: Okay.

MEMBER GROSSMAN: So I was concerned about the length of that line, the caregiver trajectory or caregiver concerns, whatever you want to call it.

I'm not quite certain why you don't include this over patient population at risk I should say, over that first bubble. You started at symptom awareness, initial detection.

What I'm thinking about here is that families are quite concerned about familial history and whether there are lots of folks that are involved.

CO-CHAIR PERFETTO: This is the point that Matthew raised just a moment ago and I think we have to incorporate that in. You're right, yes.

It would change that upper line because -- for that very reason that you raised, yes.

MEMBER HASHMI: David's suggestion I like very much because then it allows us to move patient-centered, family-centered. And then if there was another tier, maybe societal tier that we wanted to add we could add that, a community tier.

CO-CHAIR PERFETTO: Yes, that's right. Yes. Okay, very good. Good. Okay. All good suggestions. Katie, you have one?

MEMBER MASLOW: If the two were below, which I think is a good idea, the person and the family, I wish there was something here that would trigger this question about who is the answerer for the quality measure.

So, a certain point comes where the family is the proxy respondent. Even if it just could be indicated in some vague way, that transfer is important.

And if they're together there maybe NQF can think of some brilliant way to just signal. Because that's a major issue which Joanne raised earlier.

CO-CHAIR PERFETTO: Some kind of shading perhaps where it's darker for the patient, getting lighter and lighter and getting darker.

MEMBER MASLOW: Maybe. I don't know. But something that would say this is a big issue in terms of measuring quality because who's the responder.

CO-CHAIR PERFETTO: Got it. Got it.

CO-CHAIR FELDMAN: So, I love this, but since we're bubbles one other thought.

It did strike me, you know, in light

of the person and the caregiver and so forth that under care/treatment/support it's not severe treatment or moderate treatment.

I realize we started out as thinking about care, treatment and support for different stages of illness. But it seems to me now the way you look at it, it implies that the support and the treatment and the care go from mild to severe.

And that it might be -- I know at the far right there it's intensive or comprehensive or I'm not sure. But somehow those adjectives don't seem right now sitting -- it seems to me it goes from something like limited or intermittent or something to -- I mean, I don't know what the right adjectives are. And if we left it this way I wouldn't complain. But it just did occur to me.

CO-CHAIR PERFETTO: Well, the staff can give it some thought.

MEMBER SNOWDEN: I think what the

problem is that care/treatment/support should be actually the stages of dementia. Then it fits. Because that's what this mild, moderate, severe.

CO-CHAIR PERFETTO: The mild, moderate and severe were the stages of disease, yes.

MEMBER SNOWDEN: Right.

CO-CHAIR PERFETTO: And so it's care, treatment and support that happens throughout different stages of the disease I think is what we're trying to convey.

MEMBER SNOWDEN: So the problem is that's not clear. That's the problem.

CO-CHAIR FELDMAN: Exactly. I know that's --

CO-CHAIR PERFETTO: Yes. Yes. And that's -- I think that's why we have the tails happening there. Because there's no light switch that happens when it's on and off. So I think --

MEMBER JANICKI: You can take mild

out of that fourth bubble and move it back to the third one under evaluation management. Because that's really the --

CO-CHAIR PERFETTO: Right.

MEMBER JANICKI: There's not a lot of care on mild basically. It's individualized supports.

Once you get into moderate and severe you start to think about someone else that should provide the support. So, it may be further back.

CO-CHAIR PERFETTO: And I think another thing that we had -- that our thinking was included in here was that this wasn't only limited to medical care. It was also to think about some of the other social kinds of things that would go on. Yes, yes.

MEMBER JANICKI: Because there isn't a lot of medical care around mild.

CO-CHAIR PERFETTO: Right. We'll take a few more comments and then we'll move onto the next topic. And I don't know what order that happened in down there. Joan?

MEMBER TENO: I'll be really brief but what would be really cool is if this lived on the web and you could click on those things to get definitions or you can get, you know, I can click on it and get the stages of dementia.

CO-CHAIR PERFETTO: Juliet will do that in her spare time.

(Laughter)

MEMBER TENO: But it would be so cool.

CO-CHAIR PERFETTO: Agreed. Lynn?

MEMBER FRISS-FEINBERG: Well, building on the social, I think David alluded to this earlier.

I'm struck with particularly for dementia how we have end of life bereavement off in the corner. And for so many family and friends and the person they experience ambiguous loss and anticipatory grief that happens much before what we traditionally think of as end of life.

So I think we're not truly reflecting everyday life and experience if we don't capture that in some way here for dementia as a whole.

CO-CHAIR PERFETTO: And again I think it's part of -- part of the problem is our scale. Because we had the little tails there to try to indicate that but our scale may be off. Chris?

MEMBER KAHLE-WROBLESKI: Regarding the staging I would avoid lumping the symptom awareness and initial management with the mild stage because that doesn't happen now.

And I realize this is aspirational but I guess I would argue that we're probably not quite there. And so I think leaving that as a separate -- because part of the reason we had that independent of the staging was really because this may happen and become in front of mind for persons with dementia or their families at different stages of the disease depending on lots of different factors.

So I think we could fix that in the care, treatment and support by just adding the word "for." So just care, treatment and support for mild versus moderate versus severe stage.

And then I think it captures it and then we're not putting it in these --

CO-CHAIR PERFETTO: And that was what was intended.

MEMBER KAHLE-WROBLESKI: Yes. And again, aspirationally, sure, the symptom awareness and initial diagnosis happens in the mild stage, but realistically I think we can keep that as a separate concept.

CO-CHAIR PERFETTO: I think that's a great suggestion. Thank you.

So, Chris, we're going to stay with you because we're going to work our way now into the vignettes. And you had submitted one and you're first on the list.

MEMBER KAHLE-WROBLESKI: So, I am

still a card-carrying clinical psychologist so I do see patients. And this was from -- I'm also on a volunteer faculty at Indiana University in the medical school there in their neuropsychology clinic. And so this was one of the patients that we had come through our clinic.

Of course all of the -- any identifying characteristics have been changed to protect the identity of the patient that came in.

This was a 73-year-old African-American gentleman who was brought into our neuropsychology clinic for assessment. And in fact he had been referred from a physical therapist at the nursing home where he was in rehab for a broken hip.

The physical therapist was concerned that Mr. A didn't seem to remember instructions from one day to the next during their sessions together.

Prior to entry into the rehab center

Mr. A lived by himself and had limited contact with family in the area locally. His medical history was significant for hypertension and Type 2 diabetes.

Notably he'd been in and out of the hospital more than five times in the last two years with episodes of hypoglycemia, hyperglycemia and falls. Hospital notes mentioned assessments for delirium but did not indicate further evaluation was done.

He did not have a regular primary care doctor. Most of his care was received at a local outpatient clinic that was connected to the hospital.

The results of the neuropsychological testing were consistent with dementia likely of a vascular etiology. He was already in a moderate stage of dementia and required subsequent support from multiple social service agencies.

Do you want me to read the part of the gaps? I mean, for me there were multiple gaps in the quality of care for this gentleman.

Perhaps most significant was the lack of assessment or referral for any cognitive evaluation during any of his hospitalizations which I think by most definitions would be considered preventable.

It took more than two years for anyone to tune into Mr. A's cognitive difficulties despite the fact that he had multiple risk factors for dementia.

Also, no additional case management services were provided at discharge from any of those hospitalizations despite the lack of any available caregiver.

CO-CHAIR PERFETTO: Thank you, Chris. And I failed to point out that your vignette was under the category of symptom awareness and initial detection as a quality opportunity.

So the next one that we're going to go onto is under the category of care, treatment and support for persons with dementia. And Dr. Tangalos is going to cover that one next.

MEMBER TANGALOS: Sure. What happens regularly with our patients is that we'll see an advanced case of Alzheimer's disease let's say in the nursing home or in the office setting. And you're seeing this person and their family for the first time.

And the diagnosis is quite straightforward. It's Alzheimer's disease. It's been there for five or six years. The patient makes the right age. But no one has ever used that terminology.

And it's really a shooting match to decide if the family is going to accept that or if they're not going to accept that. Some families tell you thank you very much, we've been waiting for that diagnosis, we can move on with our lives.

Other families are in absolute denial. How dare you say something like that.

How do you know? My doctor says it's senility and they've not addressed the topic.

And I think to help both patients, families and caregivers we've got to come up with a little bit better way of really getting into that. I struggle with it still after 30 years, knowing what the right way is and how to sound out those patients and those families. And it certainly doesn't help me that somebody has been avoiding that diagnosis for a long, long, long time.

CO-CHAIR PERFETTO: Cyndy, you're next.

MEMBER CORDELL: You got in your packets a case study that was published by a pharmacist that I pulled out.

And basically it was a female in her eighties who had issues with dementia, delirium and depression.

And the reason I pulled that out is we have a 24/7 call center. And I keep tabs on what are common calls coming into the call center.

And one common call is Mom, Dad, spouse went into the hospital. The meds were all changed. They got worse. Delirium, all sorts of things.

So it's really an issue out there that we hear about where families get very confused and upset with what happened because they felt that all these medications changed and they weren't given a lot of information why, what, what happened. And this is a true published case study.

So basically it was a woman. She was experiencing visual hallucinations, bugs and people, had confusion, disorientation, had resulted in four hospitalizations in the past three months.

At admission she was on more than 10 medications but the pharmacist dug back and had received over 20 over the past three months.

She was previously hospitalized and

was diagnosed with dementia based on a scan. And this is now -- she was in a geriatric psychiatric unit to be evaluated.

She presented with altered mental status. Her MMSE was 26 out of 30, GDS 5 out of 15. She had insomnia and decreased appetite.

So they continued to evaluate her. She did have a UTI due to E. coli. She had delirium concurrent with dementia and/or depression. At this point they weren't sure it was dementia. They were trying to resolve this.

So the treatment plan was to treat the UTI, minimize all her anticholinergic meds, differentiate between is this dementia or depression, and then reconcile everything with all the medications she was on.

So the result of this after doing this, it turned out she had a multi-resistant E. coli UTI so her UTI was not resolving. They had to switch the medication.

There was definite benefit of reducing her anticholinergics. Her delirium improved. All of a sudden her mental status cleared. She was now 29 over 30. It turned out she had depression, not dementia.

And so the takeaways are really that this medication reconciliation process can really benefit the elderly. And the article really talks about how this is just so common in the elderly population. As it was mentioned, dementia is usually comorbid with other conditions. So they're on several drugs.

And there's, again, I look at quality. And something that you can actually document is is somebody looking at these different medications and reconciliation.

CO-CHAIR PERFETTO: So, we've had some vignettes that have been provided based on some different scenarios. One being the initial symptom awareness and initial detection. Another being care, treatment and support for persons with dementia in those two scenarios that we just heard.

Let's stop for a minute and talk a little bit about some of the things that are coming out of these in terms of the quality opportunities.

We have lack of assessment or referral. How to communicate diagnosis. Medication changes and reconciliation as an issue.

Other things that people are hearing as they're hearing these vignettes as quality opportunities?

MEMBER TENO: In the background what it feels like is that there's lack of knowledge in the healthcare system. Because if there's a lack of assessment and referral maybe it's someone who didn't pick it up.

And similarly, lack of a standardized person communicating the diagnosis, or helping family members come along is also again a failure of the healthcare system in terms of knowledge possibly.

And the medication reconciliation example. This is a classic with geriatrics, you know, polypharmacy and the confusion between delirium and dementia.

So I would say for me it would be education and tools in the healthcare system.

MEMBER GROSSMAN: This is probably a very -- several things that are up on the screen. And this has to do with the notion of misdiagnosis.

I'm thinking here of atypical neurodegenerative conditions, things like frontotemporal degeneration where the patient actually has a social disorder that's a form of dementia, not a psychiatric condition, not due to a problem with medications.

Another related issue has to do with that neurodegenerative conditions don't affect just cognition but also have associated motor problems, for example.

So, folks with Parkinson's spectrum

disorders have involuntary movements. Folks with Lou Gehrig's disease, amyotrophic lateral sclerosis have frank weakness. And all of these issues have to be incorporated into the diagnosis and the plan of care and that kind of thing.

MEMBER TENO: I'm going to follow up on that comment. I think one of my concerns that I see all the time in my clinical practice is the failure to appropriately diagnose these patients.

Too often when you have someone going from the hospital to SNF no one asks what's their pre-morbid mental status. They just assume this is someone who's demented when you're really dealing with a long- lasting delirium that needs to be cleared.

So, you know, in addition to screening we need to really have some measures to include the appropriate assessment.

MEMBER KAHLE-WROBLESKI: Well, so I would add to the lack of assessment, and I think someone else mentioned this, it's that detection issue.

So it's not just that they're getting put into the system for a diagnostic work-up but if you're missing that something is wrong in the first place it's really that detection issue.

But then the other piece of it as well is around documentation and even coding issues. The diagnosis doesn't always follow people to the hospital, or it doesn't follow them out of the hospital and that's an issue as well.

Or it hasn't been -- I guess Eric mentioned it hasn't been properly explained to them perhaps by a primary care physician what it means if they get a label of just a little bit of senility.

And so I think there's underlying a lot of this is a documentation issue and a coding issue that would be related to quality of care.

MEMBER COOLEY: This is Susan Cooley. I would echo those -- just to say if there are slides to this section they're not showing on the web. It stopped at the bubble diagram.

CO-CHAIR PERFETTO: We had a technical issue that is now being resolved. We had to call in the experts, the specialist.

MEMBER COOLEY: Well, this is Susan again. I echo the issues of the central importance of an appropriate diagnosis which starts with recognition of warning signs, documenting warning signs, initiating an appropriate work-up, documenting the completion of the work-up. Having the diagnosis on the chart and then having coding issues. All of those things are in my thinking very primary issues.

MEMBER GROSSMAN: I wanted to raise another issue that is pre-diagnosis. This has to do with the notion of familial risk and families worrying about whether they or their loved ones have -- are at risk for a dementia.

In fact, there are many folks who do have an inherited neurodegenerative condition. But there are others who don't have any real risk but nevertheless there's emotional burden of worrying about that when they see that in their family.

MEMBER BAYLIS: Another area with the assessment would be appropriate lab work. I've had patients that were on a dementia unit and with appropriate lab work they were vitamin B-12 deficient. And so with appropriate intervention their symptoms went away.

The other one is with person-centered care. I have seen really engagement and patients that were not engaging or verbal that when they were exposed to music that was part of their formative years there were dramatic changes in their personality in bringing forth those memories and quite engaging and very person-centered care for them.

MEMBER REUBEN: To build on some work

that actually has been done using quality measures for dementia is where docs and health systems fail the worst is actually in areas of counseling and referring to community-based organizations.

And then there are a couple of reasons for this. One is that the average primary care physician has too few patients with this. For me it's my bread and butter, but the average primary care physician.

And you have to get good at it. It's not just the knowledge, but it's also getting good at being able to counsel people for dementia. And also knowing what the local resources are.

So this is actually not a really good quality indicator for docs, but it's a really important quality indicator for systems or practices.

And so this whole idea of after somebody has the dementia it's counseling, it's support services, it's support groups, it's caregiver services, all this stuff that drops off the face of the universe.

CO-CHAIR FELDMAN: If I may bring up another -- a very, what I hope will be a very short vignette which I think is an example of what David was talking about, the collision between organizational or institutional protocols and personalized goals.

A 94-year-old woman with moderate cognitive impairment living in a, quote, "independent" living building but with round-the-clock aides fell on the floor, couldn't get up. The aide couldn't help her get up.

The people in the building, the independent living building, have a strict protocol that you may not touch a person. You can understand that. I mean evidence is like understandable here.

The aide had been trained in identification of stroke, you know, quick identification of signs and symptoms of stroke.

This 94-year-old lady was my mom. My husband and I were on our way back in the car from Boston about an hour away from where she lived. I got on the phone with everybody. That didn't work.

We called the EMT. I personally spoke to the EMT and again they had gone through the quick signs and symptoms of stroke.

And she was moving around on the floor. There was nothing obviously injured. And I said to the EMT, you know, I have power of attorney, everything. Go look on the door. And if my husband and I were there we would help her get up and the day would progress.

And the EMT said anybody with -- and this was inclusion in the denominator and the numerator -- anybody with signs of cognitive impairment must go to the emergency room.

So by the time we got into Manhattan my mom was in the emergency room. And because again there were no obvious signs of injury or stroke it was about six hours till she was seen by the physician. My husband and I were there.

And when the physician, thank goodness somebody sensitive to geriatrics finally interviewed us and my mom she said to me you're telling me that you would have picked her up off the floor and you wouldn't have come. And I said yes. And she did a quick one-two-three and she said we're not doing a CAT scan or whatever. You don't want a CAT scan. We went through the whole thing. Goodbye.

And so I think that's an exact example, a very poignant example of multiple institutional protocols all done for good reasons which taking into account cognitive impairment but worked against personalized goals.

CO-CHAIR PERFETTO: Katie.

MEMBER MASLOW: I'm just struck by how complicated this is. So we heard three vignettes and now yours also, Penny. And extremely complex.

And I think that maybe this is some of what Joan was talking about when she was saying messy. But it's critical to get that into the measure.

So we're not measuring a single condition in a person. We're measuring Penny's mother. We're measuring your person who probably had depression a little bit, a little bit of dementia and the delirium over it.

And I think that a problem that's pervasive here is the failure to detect and acknowledge and plan as if dementia was important in care of older people, or non-elderly people who have a diagnosis or have a condition.

I think that the pulling apart of trying to find these measures uses that overarching concept. This is very important for the care of coexisting conditions. It's likely to be messy. It's likely -- you're looking at a lot of different providers in the community, a lot of different people in the healthcare setting.

And somehow we have to -- I've heard this described as looking at dementia as the organizing principle for care of people. And I don't know how to get there more, but it certainly comes out as we're listening to all of these things about the vignettes. None of it is simple at all.

MEMBER CORDELL: Just to add to none of this is simple. One of the reasons your mom might not have been picked up is some insurers of assisted living facilities will not -- I mean it's actually mandated in their insurance policy that if anybody falls that they have to go to the hospital.

And I do think that is an issue with this. We're also butting up against other liability issues and insurance issues.

MEMBER COOLEY: Susan Cooley. That's

why having the discussion up front about what your advanced care planning goals and directives are for an individual person, what those are and having them documented, and then getting the whole healthcare system to act on what you've already documented, but at least having a document. Just having the discussion, documenting the individualized goals, then one might say under those circumstances we had already determined that if such and such happens then we're not going to take such and such action, or that we are going to take such and such action.

But the healthcare system has to have the flexibility to allow individuals to accept or decline certain care under various circumstances.

Maya Angelou, I don't know actually what happened to her. Not Maya Angelou, Ann Davis, the Brady Bunch person who apparently fell and had subdural hematoma, didn't wake up. I mean, I don't know the circumstances but these things happen. People fall. Something could happen. Some families will want to have everything done. Others will not.

That's why you have to have the discussions early on, documentation. And the healthcare system has to actually act in a flexible way on the individualized goals.

CO-CHAIR PERFETTO: Thanks, Susan. I'm going to jump to the next vignette. It's my own. And it takes us to this discussion I think about dementia sensitivity.

And it's not really about diagnosis because it's actually about my husband who was diagnosed with chronic traumatic encephalopathy at the age of 56. And I took care of him at home for eight years before he was put in an assisted living facility for dementia patients where he was cared for.

And it was not a nursing facility or a skilled nursing facility, it was assisted living, but specifically for patients with

Alzheimer's disease and dementia.

And they contacted me one day and said something is going on with his knee. It's really swollen. We're not exactly sure what happened to him, if it's some kind of arthritis or he fell down, we don't really know.

Went to see what was going on. His knee was very large. He was pretty moderately demented at that point. And they have a physician for the facility but I had to take him to a specialist myself.

So I called, I made the appointments. And I spoke with the woman who was the scheduler and said I'm bringing in someone who has some pretty severe dementia.

It would be good to have the earliest appointment in the day because he's freshest in the morning and quiet is good, not a lot of people in the waiting room. I don't have anything open at that hour. Nothing, nothing. I can put you on at 1 o'clock after lunch and things are pretty quiet then because we're restarting. So I said okay, 1 o'clock.

So I'm there. And it was a total complete fallacy that there would be no one there. The place was packed with people. The TV was on. And I said okay. I warned you about what was going to happen if he got agitated in this environment.

And my husband was about 60, maybe close to 60 at that point, maybe 59. But he was 6 foot 2. He still weighed 225 pounds. And I said he will tear up your waiting room, you know. But they didn't listen to me.

And so I sat there. And I kept him as occupied as possible with, you know, M&M's and TV and things. Didn't matter.

He proceeded to scoot himself across the floor of the waiting room sitting in his chair which didn't have any wheels on it. He just kept scooting across. And freaking people out around the room.

And finally we got seen after --

being seen long after 1 o'clock, finally maybe 2 o'clock. And I was like, I just sat there looking at the staff who are looking at me. And I was like told you so. You know, what do you want me to do? I tried to prevent this from happening.

He got seen by the specialist who had looked at his X-rays and everything and said just looked like it was an injury. Had no idea what the cause was. Gave him a cortisone injection into his knee. And he said that should resolve and if it doesn't let me know. And if this comes back again we'll have to do a work-up.

And I just said well, if it works and he comes back again we can just get another cortisone injection. And he proceeded to look at me and say no, we can't give him repeated cortisone injections. And I said why? Why not? What's it going to do to him?

And it was kind of like I could see the light bulb go off where he was like oh, I get what you mean. Yes, we could give him repeated cortisone injections, couldn't we. Yes.

And so I felt like I had multiple quality opportunities in that experience where as a caregiver I tried to prevent a scene or a problem for them.

And no one was listening to me. All along the way no one was listening. And I think dementia sensitivity up on our list was one thing that was really important to me coming out of that.

We don't -- outside of an organization or an institution that is specifically taking care of patients with dementia the rest of the system has no dementia sensitivity.

I believe, Matt, you are next.

MEMBER JANICKI: I don't know if you had a chance to read over the one I sent you, but from the area of intellectual disabilities this situation of the woman that we wrote about is fairly typical.

She has Down Syndrome. She's in her early fifties. She showed all sorts of signs of decompensating, memory loss, disorientation, other factors that eventually led to her kind of becoming dysfunctional independently. She was fairly independent up to that point where she even was married which is not untypical in many people with Down Syndrome. She had worked and she had a fairly good life.

Her mother, interestingly enough, was actually working in a memory assessment center for people with cognitive problems and asked her colleagues, geriatric psychologists, neurologists, others to take a look at her.

They came up with a diagnosis of depression which was totally inaccurate. And they put her on medication which had no effect and she continued to decline.

Subsequently she became much more agitated and aggressive and her husband couldn't cope with her. She had other problems. She had lost her job obviously at this point. She was becoming much more physically dysfunctional as well.

And they did a re-diagnosis and I think at this point the light went on and said this is something more problematic than depression. So they diagnosed her with Alzheimer's disease.

I have to point out that at age 52 it's not untypical for people with Down Syndrome. The average age of diagnosis and onset in people with Down Syndrome is in the early fifties so this woman was at par. In relationship to other people she probably would be classified as early onset. But in relation to Down Syndrome it's not really because of the compressed life and other issues.

The issue that this brings up is a number of other factors. The care then fell upon the mother because the organization that actually took her, the daughter in to provide her with some services after the job fell apart and everything else was overwhelmed by the dementia symptoms. They weren't prepared to deal with someone at that level.

They often aren't prepared. These agencies just to give you a framework here are often prepared to deal with people who have severe multiple disabilities, but not when they go through decline. And the overwhelming dealing of someone who's an adult, who is functioning at this issue in terms of these presentation of symptoms is sometimes difficult for them.

So they discharged her from the system and the mother was then left without many resources. She was again associated with a major memory clinic in a hospital. They weren't terribly helpful to her even though she was an employee there.

She then took on the prime responsibility for caring at home and was in contact with another organization who was much more sympathetic to providing care for dementia. So that woman, the daughter is now in care of the other organization in the day program but still lives at home.

But the problem that woman was experiencing was this issue of trying to figure out who could help her.

She went to the aging system. They were really unfamiliar with Down Syndrome and said this is not our area of expertise.

She went to the disability system. They were kind of overwhelmed by the dementia issues. And so she was kind of falling in between.

It's not untypical from what you saw in the list of things here in terms of the misdiagnosis issue. The lack of understanding. The kind of failure to respond to an issue. Putting the onus back on the family to provide the care because they don't have the capacity that other organizations do.

Luckily at this point she is under the care of an organization who's sympathetic to the mother's issues and is providing respite for her and supports at home. And is providing also a day service for the young woman who is affected.

And as you saw maybe from the writeup here, the mother is just kind of virtually watching her daughter basically die, you know, decline precipitously and moving along very quickly with the course of the disease.

And like I say, this is not untypical for people with Down Syndrome. It's a little bit more atypical for people with intellectual disabilities in general, but this is an issue that's systemic.

And I bring it up because I think it's important to recognize that there is a subpopulation that needs similar types of attention and services. All the issues that we've been talking about in this list apply here as well.

With the exception essentially that you're dealing with people who need also a focus within the organizational systems that provide them with lifetime care.

And one of the things that we're trying to do with the national task group is orient our own system to be more sympathetic to dementia. And I think we're having some success. But again, this is an issue that still needs more attention.

MEMBER REUBEN: I'm struck by the co-leaders' stories and this whole issue of dementia sensitivity.

I heard two things from those stories. One was the commonality of the dementia insensitivity, of the EMTs, of the rheumatologist's office not being able to accommodate this person.

And let me just say that -- I mean, I know we're getting ahead of ourselves here, but put on the parking lot for later is to think about a quality indicator of a healthcare system and whether they have accommodations for people with dementia. Which would be a big improvement and something that could be measured. It's actually a structural measure. Maybe a process measure.

Second, I also -- and this gets back to Penny's case as well, is this whole idea of personalized care. And options that would make sense for other people in terms of the work-up of this knee, you know, is just -- or a work-up of the fall, just are off the table.

And some of this is actually picked up with PULSE forms, et cetera, which do kind of trump everything. But it's not enough. It's not enough and it's a very specific situation applying to end of life and feeding and things like that. But it's not enough.

There needs to be some kind of a way in which personal preferences trump the health system.

Because the health system is designed to provide healthcare. It's not designed to accommodate personal wishes.

CO-CHAIR PERFETTO: I think another thing that I would also point out, David, is that in our scenarios we're both knowledgeable and we're not shy wallflowers. And so what happens to the people who aren't knowledgeable and who are afraid of the healthcare system? You know, those are the people I really worry about.

MEMBER BAYLIS: Through the stories I heard several concepts that I don't see on the model that we might want to consider because they were spoken of in a very passionate way that these things are very important to this group.

It started off with family health assessment, that maybe on that end there needs to be more opportunity there for family health assessment.

And then also the person-centered care.

Under the end of life and bereavement

maybe more about advanced care planning and anticipatory grief and loss along the continuum.

The one that really intrigues me is this community dementia sensitivity. I've been reading about the work in England where there's a whole movement that in communities a bank, a grocery store, a shoe store, whatever, can apply for a grant and create sensitivity around dementia.

And there is a universal symbol in England that lets people know that that business is sensitive to dementia people. So if you come into the bank we will know how to take care of you and how to engage you. And we will have an understanding and we will have patience.

And we don't have that movement here in America. Maybe we need to explore that more. I see some heads, shaking your heads about that.

And there's a lot of work by the

Bradford University and they have person-centered care training that some of you may be aware of. So those are things that I think are like big things that we need to be perhaps addressing in the future.

MEMBER STAPLES: Yes, to add to what Barbara just said. She stole some of what I was going to say.

But in addition to that I think in the model when we talk about education for the caregiver I think education for formal health caregivers, the health professionals would also be in the case.

Because with the exception of probably the neurologists and the geriatricians in the room a lot of other physicians don't come in contact with that. And I've had some serious problems with some orthopedic surgeons in dealing with people with dementia.

CO-CHAIR PERFETTO: Yael, you were next on the list.

MEMBER ZWEIG: So, this is a case of a 74-year-old gentleman that was brought in for a memory evaluation accompanied by his wife.

And so in sort of sitting down with her and listening to the history about 10 years prior to his evaluation she was noticing that he was acting out his dreams and falling out of bed.

And then he kind of had some slow changes in memory, you know, pushing her, looking back about seven years. And she kept bringing him for evaluations, and she kept being told that either he had dementia or Alzheimer's disease or age-related changes.

But she was really concerned about other symptoms where she thought he was sort of swatting at things in his visual field. And he had to stop driving because of some visual misperceptions. And she just felt like he was moving much slower and stiffer.

And she really on her own kind of sat

down and looked back over the years and had taken him in to see several different practitioners and neurologists. He had gone for multiple evaluations.

And so she did her own internet research and really thought that he had Lewy body dementia and ultimately brought him in for an evaluation at which point her suspicions were correct.

And so I thought this case was interesting to just kind of think about the caregiver's piece of this which is just the degree of burden.

Often when we think about caregiver burden it's really about sort of behavioral manifestations and care and the like. But really there is a level of burden also associated with the delay in diagnosis.

And you know, there's a cost to the healthcare system in terms of all these multiple evaluations.

And I also wanted to kind of

highlight a case looking at something other than Alzheimer's disease because as other people have mentioned when presentations are atypical or unusual often this does contribute to the diagnostic delay.

And once caregivers are given a formal diagnosis, not just dementia but be it Alzheimer's disease, frontotemporal degeneration, Lewy body dementia, whatever the case may be, there's a whole host of services that are specifically available to that caregiver population that I think without having that formal diagnosis that they're not -- they don't know about, they don't have access to, they're not privy to that additional helpful information.

MEMBER FRISS-FEINBERG: Mine is a personal story. My father lived in a nursing home for the last four months of his life. He died when he was 94 after being cared at home for 7 years by my mother and 4 different home care aides as well as my 2 sisters and myself although we lived -- my sisters and I lived at a distance.

And I was at the nursing home towards the end of my dad's life and I realized that he was dying. And I went to the nurse on duty in the nursing home and I said my father is actively dying. Nobody has talked to us about hospice care. Do you think that would be appropriate.

And she looked at me and she goes oh, what a good idea, Lynn. She said most families wait until the last minute. Why don't you go down the hall and ask the social worker. I'm a social worker by profession.

So I go trotting down the hall to talk to the social worker. I had to do everything to contain myself because I was there as the daughter. But as many of you have said because we work in the field the impact on us I think is different than for those that don't have the information.

The social worker said the same

thing, what a good idea, Lynn. Most families wait till the last minute.

So I was just flabbergasted. It's like isn't this your job as professionals to refer families to appropriate services that might be helpful to the person and the family?

CO-CHAIR PERFETTO: We have a couple of vignettes that are from outside the committee but that the staff are going to read.

MS. MYERS: So, we solicited additional vignettes from the Advisory Council for the National Alzheimer's Project Act. And we received two additional vignettes from them.

The first vignette was sent to us from David Hyde Pierce. And he was in touch with the Alzheimer's Association chapter that he is involved with in New York City. So this vignette is from the perspective of a hospice nurse provided this vignette to the Alzheimer's Association chapter.

"I spoke with a couple who was providing care for the husband's mother who was in the last stage of the illness. The couple had done an immense amount to coordinate care and supervision after their mother had started wandering but they were feeling uncertain of how to ensure that they continued to support her in the later stage of the disease, particularly now that she was bedbound and unable to participate in a lot of the activities she had previously enjoyed.

"They were grieving this decline and this was translated into feelings as if they were not doing enough for her. Their visits involved reading to the mother, bringing her flowers and giving hand massages, but they questioned the value of this engagement and felt they should be doing more.

"Counseling them involved validating everything they were doing and discussing its benefit given the fact that it focused on engaging the mother's senses. They thought reading may be frustrating for the mother because she could no longer comprehend the text, but we talked about the value of the tone, flow and intent.

"I also supported the fact that if the activity was enjoyable for the couple to do for the mother then it was beneficial for her as well.

"We discussed additional ideas for supporting quality visits, including music, reminiscence through family photo albums, and the creation of their own connect books. They were elated about these latter ideas because they felt they would be helpful for giving their young adult children ways to remain involved with their grandmother as they were struggling with visiting when there was not necessarily a response.

"I remember this case so well because the relief that the couple expressed at being told that they were doing the right things and that they could still offer so much even in the late stage was palpable. It clearly alleviated some of the caregiver guilt they were feeling."

And we had one additional one. This was also from an advisory council member, Geri Woolfolk. She acts as a caregiver advocate.

And she said, "I just spent an hour on the phone with a woman whose husband after two years of seeing several doctors had just been officially diagnosed with Alzheimer's.

"Unfortunately the woman was not given any information on what she should do next or what she should expect. She knew nothing about community resources, where she might find them, the Alzheimer's Association, the support groups, or the groundbreaking work several universities are doing in research. She said she knew nothing. Unfortunately this is not a unique situation."

MEMBER BARTON: Thanks. I just wanted to mention that, Lynn, what you were talking about made me think about the fact that insurance plays a role here. And many nursing homes I think are reluctant to call in hospice because of the way the financing works. And I suspect that this is more than this group wants to take up.

But you know also, Eleanor, as you were talking about the story of your husband's interaction with the care system it made sense that there are of course a whole spectrum of people who are entering palliative care for one reason or another, whether it's dementia, or cognitive impairment, or another reason, and how unequipped our system is to recognize what's the appropriate adjustment of care to seek to help someone with their symptoms.

CO-CHAIR PERFETTO: Treat a person, not a knee. Any additional comments? I think we're starting to hear the same themes in a lot of what we're talking about. And I think we've -- Joan?

MEMBER TENO: I want to give a little bit of a different vignette. And this is one

I've already published but it happened to me when I was on call.

I had someone who was at home, moderate dementia. The caregiver had to step out and the next door neighbor took over. And this patient had dysphagia.

The next door neighbor fed this patient with dysphagia a peanut butter and jelly sandwich. We ended up having to call 911, send the patient to the ER and required actually ICU stay with bronchoscopy to take out one peanut butter and jelly sandwich.

We had to report ourselves to the state because of this. But I think, you know, I ended up writing an entire article with a group of four people about this. What's the reasonable expectations for safety in the home setting when you're not there 24 hours a day.

CO-CHAIR PERFETTO: Matt, you had a second vignette. Did you have a second one?

MEMBER JANICKI: The vignettes all kind of point to the same problems and that's the issues of accurate diagnosis oftentimes.

The problem that we have in our field is that there's a confusion among many diagnosticians in terms of what's the disability and what's the condition. So they may not understand that the person has a dementia presentation when they look at someone with intellectual disability because they're looking at someone with low intellectual skills, cognitive deficiencies.

So they confuse the two and they don't really do an accurate diagnosis. Or they don't take the time to do it.

The other features obviously are to try to develop the right kinds of dementia-capable services to deal with people.

The nice thing about what happens in our field in intellectual disabilities is the states generally have lifetime kind of supports that they offer to people with disabilities. And it's a question of transitioning into the right type of support that's still funded and still available because of dementia.

And as a presentation the adaption of services to be more dementia-capable is a critical feature. And that's the challenge, for us to get state planning organizations and state disability agencies to think in terms of the life span and how do they adapt their services to deal with this population.

The main thing is to prevent institutionalization again. Oftentimes for people who may have been institutionalized early on that now have been living full lives and they end up back in institutions or first-time institutionalization in nursing care or whatever where they become less than apt citizens of the homes because the lower the totem pole of desirable clientele.

And so we've been sort of promoting the notion of developing community-based services, dementia care services. So those are really the issues I think in terms of the diagnostic challenges we have to find the right diagnosticians who understand the discrimination of the condition.

And the adaption of services in the community to deal with the treatment and staging issues, and all those features that go on.

The other vignettes kind of all point to the same thing and those are the main issues.

MEMBER REUBEN: So another area that I don't think has been touched yet is this whole coordination between two systems, one being the healthcare system and the other being the community-based system.

And in fact these two systems don't talk very well and don't work very well together. We've had a number of issues not only communicating, not only including HIPAA types of things because there are some barriers, but those are actually pretty easy to overcome.

But actually how information is transmitted, who answers the phone, et cetera.

And if services are provided by community-based organizations how that information is transmitted back to providers and how it's paid for. And how it's paid for.

And one of the issues here is that CBOs are, their financial model is completely different than the healthcare model. The healthcare model by and large is fee-for-service. Even if it's managed care there's some accountability in terms of what's done.

With CBOs it's mostly block grants. By and large it's block grants, it's philanthropy and things like that. And they put the money where the holes are. You know, that's just what they do.

But these are two different cultures. They're completely different cultures. And it's truly an obstacle to providing comprehensive care that bridges both health needs, medical needs and social needs. This is a paradigm disease where both needs are equally important.

CO-CHAIR PERFETTO: And in terms of transitions of care it's not just transition within the medical system where there are holes, but it's transition between these two different systems and the back and forth. It's much more complicated than just saying it's transitions of care.

MEMBER REUBEN: Oh, sure. Or co-management. You know, there's many patients who are receiving care at adult day centers or having case managers privately paid, et cetera.

And they're operating in totally different spheres. They have their own care plans and they don't see the medical system's care plans. They don't interdigitate. These are two universes. It's like alternative medicine in a sense.

MEMBER MASLOW: It's hard for me to think of how NQF is going to translate this.

And I'm thinking about Matt said dementia-capable. So dementia-capable is a concept that I think a lot of people have an idea what that means.

And Jane Tilly who's here has written about that issue. It's talking about dementia-capable systems.

And I wonder if it would be useful to NQF and if this even would fit into a report or a document to use some of that literature to say this is what we're talking about.

So when NQF asks us repeatedly what is good quality care, or what is bad quality care that we're trying to fix I think this concept dementia-capable actually has gotten somewhere in terms of thinking about it.

There are some state programs that are trying to make it happen with ALA funding. And I wonder if getting that to NQF might be helpful. And just that concept dementia-capable might be helpful in pulling together some of the ideas we've heard.

CO-CHAIR PERFETTO: Let me add another vignette because it's actually -- when we've heard some I think downer vignettes I want to give you one that's a little bit cheerier.

In the same way that I had to take my husband to have his knee taken care of I had to take him to a dentist because he had a crown that was coming off. And the little Winnebago dental clinic that would pull up at the assisted living facility just couldn't handle doing that kind of work.

And they said he -- they were also afraid to do that kind of work on him because they thought if he got agitated that -- he was very large and he would become disruptive. They thought he needed to be knocked out to have this work done.

And so I got in touch with another specialist dentist down the street from the facility who did do -- would actually use anesthesia if necessary.

But I gave him the same drill. I said he has dementia. It's pretty severe. Could we have the earliest appointment of the day. Could it be quiet with no one else there.

And fortunately for me the woman who I was speaking to was the wife of this dentist who runs their practice. And she said be here at 8 o'clock in the morning tomorrow. We'll take care of it.

There was no one else there. The new age music was playing on the sound system. The TV was off. He went straight in the door, no sitting in a waiting room, straight to a chair that was waiting for him.

And he absolutely needed nothing. He did not need to be knocked out. He fell asleep as soon as he was lying in the chair. He got his dental work done.

And so if someone is dementia-sensitive and dementia-capable it can be a very easy experience for the patient and the caregiver and the facility where the care is being provided.

So it can happen. I've seen both extremes. It's just a matter of whether or not an office, a facility, whether or not they have in place and in their right sensitivity to do those kinds of things. It can happen.

CO-CHAIR FELDMAN: And then the authority system.

MEMBER KAHLE-WROBLESKI: You know, I think the other thing, Eleanor, listening to your story, again it's because there's a good conscientious caregiver involved.

But I do think there are potentially different issues for those that don't have a caregiver, a formal one or they have children that don't live close by that can attend to them.

And that's pretty significant to have someone that can't really negotiate the system because they have dementia. And they also don't have anyone to speak on their behalf.

And so then I think you have to think very differently about what good quality care looks like when they're completely dependent on a paid caregiver of some sort and completely dependent on the system to make sure that they're cared for adequately.

And also that someone is going to take the time to figure out what their wishes are. Because they may not, again, be in a situation where they can clearly articulate what they really want to see happen with themselves.

CO-CHAIR PERFETTO: The direction you'd like to see this go in for further discussion?

MS. JOHNSON: I think this got to most things. Because the idea of this was just to get everybody's juices flowing so that when we break out into small groups after lunch and start thinking about those measurement concepts. And you guys have already articulated I think most of those.

Since we have a little bit of time before we open up for public comment a couple of things that I didn't hear come out. And I was taking notes but I was doing a couple of other things too so maybe I missed it.

But I didn't hear a whole lot about the health of the caregiver. I heard about some caregiver stress and burden, but not too much on stress.

And then going back to Eric's point of the different family engagement. Is it just education or is there a little bit more there?

So maybe, we probably have a few minutes if those two issues we might could flesh out just a little bit more.

MEMBER KAHLE-WROBLESKI: So we've done some research looking at -- we're not sure that they're caregivers, but we've looked at spousal dyads in Medicare and we do see that the spouse of someone that has Alzheimer's disease does have significantly higher costs than their age-matched controls. So we've seen that there's something there, right?

And so you don't -- again, there's an issue of those that don't have a caregiver, but then for those who do it almost makes sense to think of that as a caregiver dyad.

And so then what kinds of outcomes do you have for that dyad not just for the person with Alzheimer's disease. So what are the optimal outcomes for someone that has to take on 100 percent of the burden of caregiving.

And what does that look like. What sorts of assessments are needed to make sure. Because it does go back to the patient, and it does go back to the person with Alzheimer's disease because if their caregiver doesn't have the appropriate treatments, if they're neglecting their own health, if they don't feel like they have adequate support then that starts to impact their ability to care for the person with Alzheimer's disease.

And that's a big problem for a healthcare system when they're getting really good care by a lot of these family members. And if it's not addressed appropriately. And some of that is training, some of that is people not knowing when or how to engage with the family caregivers. And so it becomes a much larger issue to the system which by the way is already costing the system money.

MEMBER CORDELL: I'm going to give a little vignette that will cover a few of those. My father-in-law died of Alzheimer's disease. And I had a mother-in-law who was the caregiver who was in total denial. Basically just didn't want to deal with this.

And he kept driving when we kept saying he shouldn't drive. Finally my brother-in-law just went over and ripped the battery out of the car. That was the end of that.

So I think there's also when we talk about caregiver burden there are caregivers out there that the actual caregiver, other people have to get involved because sometimes that caregiver doesn't want to.

And she was also somebody that did, it took about seven months for diagnosis and it was depression, it was Lewy body, it was Alzheimer's. I mean, there were so many things thrown out.

So when he died, she wanted to know. So she paid for a brain autopsy and it was mixed. It was Parkinson's and Alzheimer's disease. And I think that's another thing, that there's often many mixed cases out there. So there was the shuffle and on and on and on.

So a little bit about -- this was actually a caregiver, affluent, got educated, didn't want to do anything, didn't want to do the support group no matter how much we tried.

And we finally did give her respite every Friday in adult day center and that was the other family members stepping in.

But I think these are some of the

challenges with this disease and caregiving, that you can give them the education, you can do everything absolutely right, but maybe that caregiver just doesn't want to respond.

And that is an issue that when you measure you can't fault a health system if they're doing everything right but the person that really needs to take the action won't take the action.

MEMBER REUBEN: Getting back to the issue that Karen raised that Eric had raised. The whole idea of having a case manager or a care manager who, one, knows the patient. It's not just an 800 number, they actually know the patient. And that can answer questions. That's the biggest deal.

I mean, if people call, they have questions. How do I find this. How do I find this. What do I do in this situation. What do I do in that situation.

It's not these generic things, it's kind of where do I find a Farsi-speaking support group. Where do I find that?

And we had a lot of experience with this with through our dementia care program. And these are really silly kinds of things. It's like finding underwear, basically Depends type of things that don't look like Depends things. They look like underwear. And for a patient with dementia that may be an incredibly important thing. It seems like small things but it's really important.

Helping people apply for Medicaid. Enormous issues. I mean, these are the kinds of things that are just under the hood you don't think about but it's what care managers do. And having that kind of a resource available to somebody can make all the difference in the world. It just can.

MEMBER TANGALOS: Yes, I struggle between the issues of denial and learned helplessness. They're the same issue.

And so we talked about denial of patients and families. We also have denial within the healthcare system as well. We have a tremendous amount of -- and again, it goes back to my vignette. I mean why wasn't the ground paved better for me to step into the situation?

And we have a lot of physicians and providers who just won't entertain the diagnosis. And it makes it tough down the line.

And they don't entertain the diagnosis. And we've dealt with this at the Alzheimer's Association for years and years because it takes more time. It's a bigger effort. You get into more and more cascades of difficulty.

But now that we have a legitimate diagnosis of Mild Cognitive Impairment, in capital letters, we have physicians and practitioners all over the place that diagnose mild cognitive impairment in small letters when the patient really has a far advanced disease. And it's a misuse of terminology, in my estimation, intentionally so that you can just get out of that situation and not address it further.

So when I hear about the caregiver denials I think about the same issues of learned helplessness among the provider community as well.

CO-CHAIR FELDMAN: In some parts of the healthcare system we also have really built-in strong barriers, formal denials to recognizing the caregivers.

So, for example, in the field of Medicare and Medicaid certified home health which I happen to know well it's very clear, you know, the regulations very clearly state that -- and the term is "patient" not "person" --- you know that the patient is the person receiving care, not the caregiver. There are very clear bounds around what you cannot do for a caregiver even though they're often a unit in the household and it's difficult to separate them out.

And the little bit of empirical research that's been done around this. And some of it, it's mostly qualitative that I've seen, describes the formal caregiving system and the informal as kind of ships passing in the night.

And yet, the other part of this very much takes into account how much informal care is available and is sure that it won't provide home health aide services or whatever even for the intermittent certified home health visit that could be covered by the informal caregiver.

So there's kind of a paradox there. I'm sure it's not the only part of the system. Part of it is, as you said Eric, that it costs more in a physician's office or anywhere to deal with the family, at least in the short run and it's not paid for.

But I don't know that this is a quality indicator, but it might be part of a report that talked about some of the challenges and barriers in the healthcare system of denying the importance of the caregiver in these situations.

MEMBER TANGALOS: You know, it was over a decade ago that the only diagnosis that was useful in Alzheimer's disease was a 301 diagnosis. It was in the psychiatric literature. It was a psychiatric CPT code.

And Katie, we took that one to task here in Washington and said that it was discriminatory to list those patients with Alzheimer's disease as having mental health. Because making that diagnosis puts you in a -- you were down 20 percent in your reimbursement. So, these barriers have been around for a long, long time.

We've gotten rid of that. That one's gone, but there's a lot of inherent barriers to all of this.

CO-CHAIR PERFETTO: Well, I want to thank everyone who provided the vignettes. That was really very nice of you to put the information forward, especially the personal information. I can appreciate that.

And I think it led to a lot of really good discussion, as we hoped it would. We thought throwing these out there, real situations, would get everyone's mind going on this to get us off to a good start for the work that we're going to do this afternoon.

Karen, do you have a comment?

MS. JOHNSON: Juliet.

MS. FELDMAN: So at this time I think we want to open the floor up for public comment. So we can invite those in the public attendance to make comments. And we can also, Operator, open up the lines for any public participants on the phone.

OPERATOR: At this time if you would like to make a public comment please press star then the number 1 on your telephone keypad. Again, that's star one.

And there are no public comments on the phone lines.

MS. FELDMAN: Okay, then we are ready for lunch. And we will be reconvening I think at 1:30. Is that correct? 1:30. Thank you.

(Whereupon, the above-entitled matter went off the record at 12:42 p.m. and went back on the record at 1:28 p.m.)

CO-CHAIR PERFETTO: Okay, we are going to get started. We have a group activity that's going to be happening this afternoon. And Karen is going to review the committee exercise.

MS. JOHNSON: Thank you, Eleanor. Hopefully everybody enjoyed your lunch and had a few minutes to catch up on any emails or that sort of thing and chat with your neighbor.

So, the fun really starts now. We're going to break out into small groups and do a first round of prioritization.

So I want to do a couple of things before I have you guys split out. So, first of all, what's the goal of what you're going to be doing?

Well, the goal is to come up with two lists of prioritized gaps. Your list, each list should have somewhere between three and five choices for where you think future measurement should be going. One list will be for the person with dementia. The second list will be for caregivers. So I want you to think about both of those.

We have put you into groups. We tried to balance things like interest and experience and perspective. If you really, really, really want to switch groups you're allowed to do that. But we want to have five or six, seven people per group. So, however that works out.

We have about 75 minutes total for this exercise. Yes.

CO-CHAIR PERFETTO: I have one question about the groups. Susan is listed as group 2.

MS. JOHNSON: Yes.

CO-CHAIR PERFETTO: So will we have that group meet huddled around a phone or something?

MS. JOHNSON: Yes. Group 2 we will actually be meeting in a different room that has a phone. So I will be facilitating that group so those of you in that group, we'll just meet over here at the door and then we'll troop over to that room.

MEMBER COOLEY: This is Susan. I have the phone number for that that I was given.

MS. JOHNSON: Yes. So we'll break here in just a minute, Susan, probably in another five minutes or so.

MEMBER COOLEY: Great.

MS. JOHNSON: Yes. I've given in your packet that you had this morning I gave you some instructions for our small group exercise. I have some suggested steps for how you might want to approach the exercise.

So, one, I suggest that you -- well,

let me back up for a minute. The groups are split out according to the measurement domains.

So, you should also have on your desk in front of you our measurement ideas concepts grid. So, just a couple of things about that. Let me make sure I cover everything here.

This is a tool for you to use. We'll see if it's helpful or not. Hopefully it will be.

Those of you who don't know the inside joke of why we're calling it David's napkin. Back earlier when we first started this project and it was just a smaller group of you guys helping us out there was a lot of discussion about care needs and symptoms and things like that, the mild, moderate and severe stages.

And I said, David, this sounds really great. I didn't get it all down when we were taking notes. Could you scribble it on the back of a napkin and send it to us? And he actually did and that was the genesis, David's napkin, of this grid.

So, we have expanded that over time with your feedback. So thank you very much, David. So when we talk about David's napkin it's really the symptoms and needs grid and then from that the measure ideas and concepts grid.

So, a couple of things. Let's go to the next slide. Let me make sure I get these. Yes, here we go. So, our initial napkin expanded into our two grids. We've already covered that.

And these should not be surprising to you. The columns are what we're calling our domains. And those match the bubbles in our bubble chart.

And then the rows are what we call our subdomains. And those are the things that are in the trajectory boxes that are in the concepts.

So, again, this is a tool. It is not

yet comprehensive. It will never be totally comprehensive, right? There is an infinite number of ideas for measurement that could be out there.

But it's I think a good start because you've given a lot of feedback on it.

The assignments, the domains and subdomains are somewhat arbitrary. For example, I think, Katie, you might have been the one who said, okay, I see care plan but why is it under diagnosis. That one made a little sense to me but the update care plan is also across from diagnosis. That may not be exactly right.

So don't get too hung up on where things are. The idea is to try to get some concepts in each of those domains.

If we don't have concepts in those domains we have to ask ourselves are those the right domains and subdomains for measurement.

The exception right now is prevention. There's nothing in that prevention subdomain.

And maybe that's because we're not there with the science. Maybe we just haven't thought of one yet. So that's for you guys to discuss.

There is quite a bit of repetition. Some of these concepts, and I think I heard somebody this morning say this. I heard it out of the corner. A lot of these things kind of show up several times under several of the bubbles. And that's okay because when you're doing assessment you don't just do one assessment and you're done, or one treatment and you're done. These are things that have to happen possibly a lot of times over the course of care.

And then finally, the concepts that are on this sheet we tried to get high-level. And some of them are a little bit more high-level than others.

But for example, when we talk about doing assessment for the signs and symptoms of dementia we didn't actually go in and put down all the different signs and symptoms of dementia. Because that is the job of the measure developer down the road.

So our job here is to come up with the concepts and prioritize those. And we leave the work of specifying the measure to someone else down the road. So we don't have to get too much in the weeds here and hopefully that's pretty clear to you.

So what we're going to do when we break out into our groups. I would suggest doing your first domain. So each group will be given two domains.

So, for example, the first one is -- group one will have population at risk and symptom awareness/initial detection. So that will be your purview, okay?

And what I suggest that you do is use some time to discuss the various concepts that might fit into those two domains. And then spend a little bit of time using dots, it's your favorite dot exercise. I'm sure you guys have done that a lot of times.

But we're going to give you -- for the person with dementia we're going to give you 10 red dots. And you will put your dots on the things, on the concepts that you feel are the highest priority for future measure development.

What we would like you to do is put no more than four dots on one concept. But you can use all 10 of your dots or not, however you want to do that.

You'll have a set of 10 blue dots for the concepts that go with the caregiver, the family caregiver. So you will have 20 dots total to distribute to indicate how you think these things should be prioritized.

And then I suggest spending a little bit of time after that to just make sure your group is with consensus, at least comes to consensus.

I'm a very visual person so on the

back I tried to show you what I'm thinking. So the first table shows you for group 1 population at risk you see the person with dementia. There is a whole bunch of concepts, A through G, that theoretically you guys have written down and then you prioritize them.

And there's four there. So those are the four that would go to the full committee. It looks like I missed one there on the full committee. But the ones that are highlighted there are the ones that would go to the full committee.

So what we'll do is you'll do your own thing in your small group and then you'll bring that back to the full committee and discuss and talk about why you came to where you came.

Does that make any sense? Okay. P You guys probably have done this a thousand times.

One more thing to talk about real quickly. What we're trying to do is prioritize gaps, right? So what is a gap?

Well, a gap could be here's a concept and we don't have a measure on it at all. That would be one way and that's kind of the obvious gap.

The other gap might be, hey, there actually is a measure out there, maybe a couple of measures out there, and they do something but maybe they don't do it quite in the way that you think would be the best way.

So, for example, maybe it is a very small population. Maybe it is a nursing home-specific measure. And you say hey, it's a great idea. Why aren't we doing this for everybody?

Or maybe it's a process measure, a real simple process measure and you may say it's really a great concept but we would get more bang for our buck if it were turned into an outcome measure or something like that. So that is possible too, to think about that as a gap.

So, however, again, it's going to be up to you to figure out how you think things should be prioritized. Okay?

So let me open up for questions and see. Barbara? Oh, okay. All right, any other questions?

MEMBER COOLEY: This is Susan. What are the two other groups? I heard you say what group 1 was. What are 2 and 3?

MS. JOHNSON: Two and three. Oh, sorry, we didn't send you this, did we, Susan. We'll try to send you this so you have this in front of you.

Group 2 is going to be evaluation and initial management. And care treatment and support, but we split that one up. So care treatment and support more for mild to moderate. And then the third one will be care treatment and support for that severe along with end of life bereavement. So that was just a way to split things a little more evenly. Ryan?

MEMBER COOLEY: And are we focusing on the grid that's called Measurement Ideas and Concepts and not the grid that's called Symptoms and Needs?

MS. JOHNSON: Correct. So the idea, the symptoms and needs should help you think of concepts, right. If there's a need then that probably would translate to some kind of concept. So they should work together, but ideas and concepts mainly.

MEMBER COOLEY: This is Susan again. Not to hog the questions but in terms of knowing what measures there are out there currently you originally provided -- not you, but you know, the group originally had an environmental scan of measures.

I don't recall having seen a crosswalk between existing measures and these grids. That hasn't been done, has it?

MS. JOHNSON: That hasn't been completely done. But the closest that I've come so far is in this ideas and concepts grid there are asterisks beside some of the concepts. And the asterisk means that there is at least one measure that hits it to some extent. So, and I don't have a good example.

MEMBER COOLEY: Oh no, that's good enough for me because that was another question, what are the asterisks. That's good to know. That's the clue that there may be something out there on that topic.

MS. JOHNSON: Yes.

MEMBER COOLEY: That's good to know.

MS. JOHNSON: Yes.

MEMBER COOLEY: Thank you.

MS. JOHNSON: Yes. Now, I will say that we do have online and it should be available to you on your SharePoint connection the environmental scan, what we have so far. But we didn't print those out. It's pretty unwieldy so we didn't feel that that would be useful.

But if you think, you know, if it turns out that you pick things that have already been done, again, it may still be a gap if it's been done as a very simple process measure but you want to extend it to an outcome measure or something else. Or maybe even an ACO-level or a population measure or something like that. So there's still room to extend potentially. Ryan.

MEMBER CARNAHAN: Yes, so if a measure exists but we think it should be applied in this setting we shouldn't necessarily prioritize it as a gap. We should just bring that up at another time that this would be a good thing to measure in this population.

MS. JOHNSON: Yes. So, and that's a good point. We will have -- we want you to think about things for parking lots so that will be something.

There are a lot of measures out there that already exist, particularly things like safety measures, falls, some medication reconciliation kinds of things that are out there that really can be applied to the dementia population.

So, one recommendation that may come out of this body is, hey, make sure that people with dementia as Joan said earlier are not excluded from those kind of measures.

And maybe when people implement those maybe you should stratify. You know, think about looking at it stratified for the dementia patients.

But, you know, it probably isn't necessary to build a whole 'nother measure just for the dementia population looking at falls, for example.

CO-CHAIR PERFETTO: And the idea behind this is to think about what concepts, what are the things that we'd really want to measure, under what circumstances. Whether or not a measure exists.

If a measure also exists, great, tack that on. But focus less on the existing measures or the measurement tool and focus more on the concept right now and getting to the tool later in the next step.

MS. JOHNSON: Any other questions about what we're going to try to do? Eleanor and Penny have great faith that you guys are going to come back with a manageable list of all the infinite number of concepts that are out there.

CO-CHAIR PERFETTO: We didn't say manageable. We said a list.

(Laughter)

MS. JOHNSON: And we suggested three to five. If it turns out, you know, six or seven that's okay. I mean, we're not counting beans here.

No other questions? Okay. Group number 1 is going to meet up here in the front. Group number 3 is going to meet back here in the back of this room. And group number 2 is going to go with me to another room where we have a phone and we can get Susan to call in and participate with us.

Yes. Toward the big screen would be the front. Yes.

MS. FELDMAN: We're going to break -- for the transcript purposes we are going into small groups.

(Whereupon, the foregoing matter went off the record at 1:44 p.m. and went back on the record at 3:34 p.m.)

CO-CHAIR PERFETTO: Okay, we're ready to get started. Everyone please take their seats.

MEMBER COOLEY: Susan Cooley, I'm here.

CO-CHAIR PERFETTO: Thanks, Susan.

CO-CHAIR FELDMAN: So, we have three groups, three reports. I think it was an engaging and challenging task.

And should we go in like chronological order do you think? No, no, no, starting with population at risk. That's the trajectory we're talking about right this moment.

Okay, Katie. And since you're not standing by your microphone how is that working?

MEMBER MASLOW: Okay, so I'm standing here so that I can look at this. I know that you can't follow. Are you going to move it?

CO-CHAIR FELDMAN: A handheld mike is on the way.

MEMBER MASLOW: Okay, so our group had two columns. So our first column is population at risk.

And we have an idea. This is a concept. It's aspirational. And the idea is some kind of sort of hierarchical system that would start by identifying people with risk factors for cognitive impairment.

So this is not looking at the screening row. This is not screening for people with -- looking for cognitive impairment. This is identifying people who are at high risk for developing cognitive impairment and dementia.

So that's first. That's this concept. And look, and using a very broad definition of risk factors, of things that could be indicators of risk for dementia.

Then, second and connected to that is trying to educate first the public about those risk factors so that people come to understand what creates risk for cognitive impairment and dementia.

And then education of the healthcare workforce about those same factors. So what creates risk for cognitive impairment.

And along with identifying risk is also identifying or creating a message about the possibility of there's something to do. So, to try to counteract the stigma and sort of fear to say these people are at greater risk but there's also something to do for them if they are identified.

Anyone in my group want to say anything else about this one? Okay.

So then we talked about in the area

of symptom awareness and detection. In this high-risk group, and again, aspirational here, but looking at the high-risk group that those individuals should be screened on a regular basis in a physician office. And screened looking for any indicators of cognitive impairment.

So that's one domain or subdomain I guess it is. Is that right? It's a subdomain? Or is it a domain? It's a subdomain. You don't want to say. I see, you won't even look at me about that question.

(Laughter)

MEMBER MASLOW: Okay, then the second thing is to be -- greater awareness, and this is essentially for healthcare workforce, social service, anyone that would be working with people who might have cognitive impairment, greater awareness that dementia is not just memory problems. So looking more broadly at functional triggers for being aware of possible dementia.

And we thought of a lot of things in this area but looking broadly at language issues, at gait kinds of issues, things that aren't what everyone thinks of as memory problems or dementia.

Then third -- or let me stop with those and talk about diagnosis. So we don't know whether our area includes diagnosis or that belongs to the next column.

But we think that it's very important that detection lead to a diagnostic evaluation, one.

Two, that the diagnostic evaluation is intentional and results in a diagnosis. That it occurs in a reasonable amount of time, that being a short time from when there's detection. And that it's documented. So as we go through that I'm sure we're into the next column's area, but at any rate, those diagnostic-related and measure-related issues.

And then two more things. That even in the area in the time of symptom awareness and detection family involvement, engagement of family is important. Assuming that it's all right with the person, but that the family at that time is also often anxious, might be depressed are issues for the family related to the detection and diagnosis.

And that they need to be -- family members need to be considered at this time. That that's part of quality of care.

And then lastly, that as the detection process moves on, and again we see this as sort of a flow from the top on past our area, that there needs to be attention to interventions that can help with quality of life of people who are in early detection and then going into diagnosis.

So what have I missed? Nothing else? Mark, anything? Murray?

CO-CHAIR FELDMAN: Great job summarizing a very ongoing discussion with many --

MEMBER MASLOW: I probably missed

some important things, but anyway.

CO-CHAIR FELDMAN: Having set that spectacular model of conciseness we're ready to go onto evaluation, initial management and mild cognitive impairment. Right? They were together. So that's our group number 2. Who's going to report that?

MS. JOHNSON: I got elected to do that. I'm not sure how that happened, so. I think because it's a little unwieldy with our papers. But my crew will definitely help me out here.

I think what we ended up doing and possibly my fault, but I really wanted to keep people separated on our evaluation and initial management, and then go into the treatment.

And then after we did that the first time, then we ended up saying hey, a lot of these things are kind of the same except for updating. So, at the end of the day I think we ended up in the same place you guys did but it took us longer to get there. But that's okay.

So for a person with dementia. And these aren't necessarily in order of importance. These are just the ones that rose to the top.

Needing to know who the proxy decision-maker is. Assessing for personal goals for treatment. Having a care plan documented and not only in the chart but given to the person.

The core dementia work-up needs to be done and documented, and along with that is eliminating other causes of dementia.

And then finally, connection to supportive services in the community. That was a big one that kind of -- a lot of things went under that one.

There may be a couple of others that I'll tell you once I get to the second sheet. Let me give you the caregiver ones. And actually some of these are the same for caregiver but we'll work through it.

Having capacity and confidence. We also, the group thought that it was important to assess the caregiver goals for treatment, knowing that the caregiver goals and the person with dementia goals may be different. And knowing, you know, understanding that.

The education on what to expect needs to be given to the caregiver. I think that didn't rise to the top for the person with dementia, but that person also needs to know what to expect too.

Thinking about caregiver burden and strain. Also, again these aren't really in order, understanding treatment options. So the caregiver needs to understand the options that are there.

And then of course the connection to supportive services in the community. That's the same as up above.

And then -- so that was what we came up with for the first one, the evaluation and initial management. And then as we walked through the care treatment what we ended up saying again was a lot of these things were the same, but we did figure out a couple of new ones.

So, under person with dementia, actually if you just go back to that other slide and just add another bullet under person with dementia. Having a dementia case manager. Is it case manager or care manager?

CO-CHAIR FELDMAN: Care manager is generally.

MS. JOHNSON: Okay. And then, team, you have to help me with this one. Transition, impacts on dementia, delirium, et cetera. Can you? Right, right.

MEMBER CARNAHAN: Yes, I think we're onto the mild and moderate piece now as opposed to initial management.

MS. JOHNSON: Yes. So, I think we're just going to group them together. Is that not what we decided? Or do you want to keep them separate?

MEMBER REUBEN: Some of them yes and some of them no. So, the ones -- this is one that would actually be in the follow-up stage.

MS. JOHNSON: Okay.

MEMBER REUBEN: Yes, so that in the follow-up stage anyone who has dementia, if they're transitioning, or they're discharged from a hospital, or to a nursing home, or something like that, the impact of that illness upon their dementia care should be reassessed. That's what we're getting at.

MS. JOHNSON: Are you happy with that bullet?

MEMBER REUBEN: It's the impact of transition of care. So in other words if they're hospitalized. Or impact of acute illness or change in condition under care.

CO-CHAIR FELDMAN: And just a point of clarification. And does the care manager also only refer to the person with mild dementia and not to the -- I mean, to the treatment and not to the -- not to the evaluation and initial management?

MEMBER REUBEN: So, this is an artifact of setting these things up arbitrarily.

So you would think actually that you would have -- basically the game would begin when there was the initial assessment and it would go on. But the way they were divided is you have this initial assessment and then the follow-up period.

So, during the follow-up period you need the dementia care manager at the time of assessment. The dementia care manager does the assessment. There's no role for that person. But it's an arbitrary distinction.

CO-CHAIR FELDMAN: All right. But someone's identified early on.

MEMBER REUBEN: Right, yes. Someone is identified early on.

MS. JOHNSON: Okay, let's see. Assessing medication side effects and effectiveness. I think -- I was thinking it was in both. But I guess it's arbitrary again, right, Dave? It's kind of arbitrary?

MEMBER REUBEN: So, it's arbitrary. But here, let's say that they have the initial assessment and they got started on a medicine. And in the follow-up period you'd assess the response to the medicine including adverse effects.

MS. JOHNSON: And then for caregiver this is --

MEMBER CORDELL: Side effects and efficacy.

MS. JOHNSON: And efficacy. Yes, efficacy or effectiveness. Yes, thank you.

For caregiver we want to start thinking about health, caregiver health being assessed.

And here we recognize that the person, the clinician that's taking care of the person with dementia may not be taking care of the caregiver but yet has some responsibility to do some referrals or something like that so that, even bringing it to their attention that they may need further health follow-up.

And then lastly, caregiver participatory decision-making. So the idea there that the caregivers are engaged in the decision-making even at this earlier stage.

I think I got them all but does that -- that seems like your list?

I think the other thing that we talked about was there's a lot of assessing at that early stage. But knowing that the assessing doesn't happen one time, but it has to be updated. So care plans are updated. Assessments are done again and again.

MEMBER REUBEN: I thought the dementia care manager was going to be in that next slide.

MS. JOHNSON: Yes, I think it may be. So that where your cursor is now --

MEMBER REUBEN: Yes, move that to the next one.

MS. JOHNSON: -- can you move that to the second slide?

MEMBER REUBEN: Yes. And what I would say for this title, I would change it to Group 2 - Ongoing Care for Mild to Moderate. Makes it a little clearer. So one is the initial assessment and this is the ongoing care.

MS. JOHNSON: Yes.

MEMBER CORDELL: Right and also like the connection to community resources should get in initial and throughout so we didn't repeat it. So these weren't completely separate.

MEMBER REUBEN: So the other thing we had for the ongoing care that didn't make it on this list is the routine reassessment of everything that was on the first. So they'd have to have periodic reassessment.

MS. JOHNSON: Yes, right.

MEMBER REUBEN: So go to the next slide. Correcting the slides. That's okay.

MEMBER CORDELL: So periodic reassessment should be a bullet that's on the second slide. Because the periodic reassessment of everything that's on this slide should happen in the follow-up.

CO-CHAIR FELDMAN: Is that it? Other additions to that group? Okay, great.

So now we go to group 3 which was care treatment and support for severe dementia and then also end of life and bereavement. Joan, sorry.

MEMBER TENO: Great. Okay, we were a group of lumpers. So we're thinking of this as for families in five sort of overarching constructs that would form multi-item composites.

So, the first one in this group would be shared decision-making with an advanced care planning composite that would cover a range of activities from informing about prognosis, treatment options and anticipating future decisions.

For example, educating people about the use of feeding tubes given that such a high rate of this population is at risk for feeding problems, hospitalizations.

The second construct is person-centeredness. And you know, I think this can cover a range of items. But one of the key things that was brought up by the group is that it would include the ability of that person and family to shape choices over their everyday activities. Whether that person was treated with respect and dignity.

So this would sort of get at the choices about what would happen for that patient on every day depending on their setting of care and interaction with healthcare providers.

Third, if you sort of look at where the money is, the money is in hospitalizations and transitions of care and the lack of coordination of care with those events. And often hospitalizations can be an iatrogenic episode.

So, it would be important to look at a trigger for transition in the brief, the family member's perception about how that transition went, how did the care in that hospitalization go.

And sort of I saw this as low-lying fruit is to deal with HCAHPS and the fact that HCAHPS now routinely excludes anybody who goes to a nursing home.

And I think this would be a case where some valuable information could be obtained about the quality of care for a population that really challenges an acute care environment.

Fourth, we realized that caregivers play a very important role. And we see a multi-item composite that would cover everything from the initial assessment done for that caregiver about sort of their needs and expectations to timely communication with the family member.

Training for someone who's going home, whether they were provided with the correct amount of information about what to expect and training and support in providing those tasks at home.

The responsiveness to their needs. I think one of the cases we heard is how -- a very poignant tale of how our healthcare environment or healthcare system was not responsive in listening to the family member about how to avoid a disruptive episode in a dementia patient.

And often we forget the caregivers are probably the best source of information about who that person is and how best to care for that person.

And then time and time again family members feel that they're left to advocate for their own in a healthcare system that's not responsive to their needs and expectations.

So this notion of a system can create an environment where they don't feel they're always advocating for, you know, I was going to say high-quality care. Often it's just basic care.

And then the fifth idea which is one I really like is why not use the family member to comment on how dementia-capable the healthcare system is. They're really sort of an expert witness about what the frustrations are.

How did people interact with that patient? Did they make eye contact? Just I think I could see easily a series of composites created which had the family member being expert witness to how that healthcare system interacted and treated that dementia patient hopefully with dignity and respect. Thanks.

CO-CHAIR FELDMAN: That's great. Any other additions to that?

Okay, so I think now -- now is the challenge of pulling this together. And I'll kind of start it off with one comment and then

I'll throw it out to others.

I think -- I'll start off the discussion with just one thought that's come up in each of the groups which is that there are clearly some constructs which while they may seem most salient or most poignant for one part of the trajectory they actually are -- they rear their heads in one way or another across the person trajectory and the caregiver trajectory.

And so it seems to me one question to throw out to the group is do we want to, and the answer might be no, but are there certain really salient things that have emerged from all of these, or that came out in one group which maybe were mentioned in another group but didn't rise to the very top which we might really want to flag as critical concepts to be measured periodically with perhaps different frequencies at different points in time.

And then the second thing that also -- I'm not saying anything that's very earthshaking.

But the second thing is that there are most likely some things which may be unique or are so salient for one part of the trajectory but not necessarily so salient for others. And that we certainly want to be sure that we don't miss those.

And so my question is is that one useful way of thinking about this? What are the kind of commonalities, things, concepts that we think we would like to capture and measure across the spectrum? And others that we believe are uniquely or principally important for one part or another?

And so I throw that out. You can say that's ridiculous -- propose an alternative.

You lost two sentences there. I said we can throw it out and we can reject it, or we can view those as some organizing principles and way to go. But it was just a way to start discussion.

MEMBER SNOWDEN: I mean, I would

certainly agree that anything that really can be relevant across the entire spectrum would be better than things that really will have a short life span so to speak within the trajectory.

MEMBER REUBEN: I agree. And I think there were some that clearly went across all three. Those include this concept of shared decision-making, participation, patient preferences. Those kinds of things go through all of these.

The second one that really goes through all these are the whole idea of caregiver involvement, caregiver support, caregiver -- effects of caregiving on the caregiver per se. I think those got through all of them. There may be some others.

MEMBER KAHLE-WROBLESKI: So yes, I think those are some great shared ones across.

The one piece we talked about this morning that Joan had brought up, it's the denominator piece.

So I think we would need to think separately maybe about the detection piece. And that's okay because I think there are some commonalities across all stages.

But I don't want that detection piece to get lost in that because I think that is critical, that's our denominator and that's what is going to drive a lot of this.

CO-CHAIR FELDMAN: Other thoughts and comments about the groups' reports back and what's common, and what's distinctive, and what we want to be sure not to lose?

MEMBER SNOWDEN: Yes, it seems to me that one of the things that all of the groups did was to actually back up and abstract at a broader level which leaves me wondering what happens to some of the fairly specific and concrete things that are actually on the sheet.

And my sense is that they can be incorporated into this but part of me wants to make sure that we don't forget the ones that are actually on here that tend to be fairly specific. Because they'll either need to be consciously put into that or something else done.

CO-CHAIR FELDMAN: It would be useful to have an example of that.

MEMBER SNOWDEN: So, for example, as a psychiatrist I was really interested in a lot of the ones on behaviors particularly when we get into the course of illness.

My group given where we were in the trajectory didn't spend a lot of time on that, but it's clearly I think very important.

I see it as one of the signs and symptoms. So to the extent that a lot of these talk about signs and symptoms. I'm okay with saying we don't have to call out every single sign and every single symptom.

But I want to make sure that, again, it gets translated into a broader concept, that that's what we're really going to do.

CO-CHAIR FELDMAN: One of the

concepts that came out of our group, and Mark, you were in that group, is that for people who are not specialists and trained to assess people with dementia and cognitive impairment is that they tend to have a list of a couple of things that they think about that are very segmented, like memory, for example, memory loss, or maybe word recall.

And that yet there are a host of non-usual suspects which are usual suspects to a psychiatrist or to a neurologist. You know, falls, gait, all kinds of things that don't get encompassed in everything from signs and symptoms to detection. Presumably in diagnosis they get picked up but then they may be lost farther along the way.

So maybe one theme going across is this emphasis on not just focusing on usual symptoms. I don't have an elegant way of putting that. Would that begin to capture what you're --

MEMBER SNOWDEN: Yes, that would be

perfect.

MEMBER HASHMI: I was just going to offer a vocabulary for what Mark was saying and what you were saying is it's a disease with multi-system manifestation.

CO-CHAIR FELDMAN: Great.

MEMBER HASHMI: And the systems are about not just the body but it's a societal system. And the health macro and micro system as well.

CO-CHAIR FELDMAN: Joan.

MEMBER TENO: I just wanted to add in addition to thinking about the denominator I'd also think about what is the trigger. So, in terms of specific time periods.

So the one thing nice about the HCAHPS example is you probably could construct a denominator, and then you have a trigger, and then you have a set of behaviors that sets up an episode of care. So that I think is really important to think about.

As we sort of develop these

overarching concepts we need to have them be able to link to a way of identifying the population, but also thinking about what the episode of care and who's accountable for that.

CO-CHAIR FELDMAN: Right. And transitions came up in several groups as one obvious trigger. And we actually -- I'm not sure, I think we did use the word "trigger" in our group. The notion of when you identify someone with risk factors what should that trigger and what actions, presumably measurable actions, should that trigger. And then when there's a diagnosis what should that trigger in the way of action.

So I think the concept of triggers is implicit in what a lot of people said. And so there could be common measures but then issues around what events trigger the application of particular measures.

MEMBER TANGALOS: When I look at our conceptual framework and try to see if we've touched on most of the pieces, not that we have to.

I think we did but where I worry the most is we haven't hit much on safety. And when I look at patients I look at autonomy and safety. I look at risk versus dependence. Those pieces kind of balance themselves out as patients go forward.

And you know, in our conceptual framework we put safety at the very end. I actually think it fits in before that too. But I don't think we've done a very good job of addressing the issues of safety in any of what we've discussed so far this afternoon.

CO-CHAIR PERFETTO: Eric, let me just add to that because I think you're right, I think we didn't cover safety very much at all.

But one thing that we talked about this morning that in the conceptual framework it's a little misleading that these are laid out, the domains are laid out horizontally like that. And it was not the intent to say that safety was at the end. It was just the way that they got laid out.

MEMBER TANGALOS: No, I understand that. I mean, there's plenty of places where we would have done that.

But still, the issue of safety I think is -- it may be because it's a late player to the game. The universe of quality now has to embrace safety.

And the next iteration of the National Quality Forum will be the National Quality and Safety Forum. I mean, it's going to be along those lines.

But I think we've got to think about it more.

CO-CHAIR FELDMAN: Katie, go ahead.

MEMBER MASLOW: So, I agree with Eric. I think that in our idea of looking more broadly at what cognitive impairment and dementia mean we started with Mark's discussion about falls.

So, very early falls. It's a risk.

It's a safety risk. Driving. All of those kinds of things where if we expanded our training and health workforce awareness of those different aspects of dementia we would see more what you're talking about, the safety issues going all the way through I think.

CO-CHAIR FELDMAN: Ryan.

MEMBER CARNAHAN: Yes, I'll just say we did talk about that. And if it didn't quite make our top five it was right up there, evaluating the safety of the environment. And that kind of went along with the caregiver capacity to take care of somebody when they're not yet in the nursing home.

MEMBER TANGALOS: I could wax eloquent on safety a little bit longer. When we start to teach about quality and safety the quality universe is oftentimes very difficult. It's in the eye of the beholder. And here we have the beholders and we're all looking at this stuff.

The safety environment, the safety

universe is actually easier to measure outcomes. I mean, it's X's and O's. It's yes or no. It's errors in a given substrate.

So again, I think even for the purposes of this exercise and as the next couple of years go forward continuing to think about safety as a measurable outcome is really the way to go.

CO-CHAIR PERFETTO: I just want to add my personal note on the safety issue. Because I think for me over the 15 years that I was caring for my husband I started with the goal of keeping him functional.

And then over time that goal changed. And it was no longer the goal was to keep him functional, it was to keep him safe and have a good quality of life, and to be sure that people around him were safe. Because if his behavior became bad it wasn't only his safety, it was others' safety too.

So I think over that period of time your goals change. And I think as you go down the trajectory safety goes up when other things start to go down.

CO-CHAIR FELDMAN: Ryan, are you going to talk to the safety? Your card's up. No.

So, I was just going to comment that outside of institutional settings this issue of accountability around safety and the tradeoffs between autonomy and safety become particularly sensitive issues for providers.

Because for most of the time the person under their care is actually not physically under their care. And so I think it's a huge area for sophisticated and developmental thinking about that. Because I think that's really been very difficult in the non-institutional.

MEMBER TANGALOS: Actually, when you look at -- I mean, we've looked at assisted living providers who over the last 40 or 50 years have gone broke with a building.

And they usually go broke with a

building when it gets down to somebody moving in and saying what do I want out of this building. Do I want the Jacuzzi? Do I want the chandeliers? Or do I want grab rails in the bathroom? And people make those decisions.

And healthcare is honestly way behind in the safety universe. When you watch car commercials today the implicit and explicit message is you are not going to die when you crash this car. That's the story.

CO-CHAIR FELDMAN: Joan.

MEMBER TENO: I think safety is a little bit difficult. It depends on sort of the population that you're dealing with.

I think the home population is a very difficult population in that we tend to allow people to have a lot of autonomy and allow them to sometimes live in a less than perfect environment because that's based on their views, choices and values.

The other thing I would worry about

is when you think about safety as sort of a checkbox measure for some populations, especially those people who are dying, some of the checkbox measures that were developed for the acute care hospital are not really transferrable to that population.

You know, sometimes we really don't move people while they're actively dying even if that may increase their risk of pressure ulcer, UTIs, things like that.

So I actually think safety, some of the safety measures we have need to be really thought through on how they're applicable to this population and where people are in their disease trajectory.

CO-CHAIR FELDMAN: And our group certainly didn't have a solution to this but we talked a bit about the issue of stratification and how that relates to who's in the numerator and the denominator for particular measures.

And I think that from a feasibility

or acceptability point of view the issue of stratification is going to be very important.

And I think that done right it could really be an incentive for providers to do a better job of actually detecting people, particularly in the early ages, and reporting people with dementia. David?

MEMBER REUBEN: Yes, let me just respond as well about the safety issue.

Maybe it was just our group that we had a larger charge or that we just generated a lot of ideas.

But I think one of the issues is there were a lot of clearly ideas, that we endorsed that we really liked, but we only had 10 bullets and we had only 10 dots. And some of them fell below that threshold of the five.

So it doesn't mean they're not good ideas. And if we had -- I think all of them we would have elected to have kept. So once again, this is something, an artifact of the process.

But we all felt it was a good idea. Not enough of us voted for it to get it to the final five.

CO-CHAIR FELDMAN: Mark.

MEMBER SNOWDEN: Yes. As I looked at the things that are listed under safety if I had to pick things out that to me would have risen to the top I think certainly falls would have been up there. I think environmental safety would have been up there. Certainly medication issues safety would have been up there. Wandering and getting lost. Safe return.

The things that I didn't see on here that again as a psychiatrist come to play are unsafe decisions because one isn't attuned to decisional capacity.

I see a lot of people who make decisions and I get called in to evaluate their capacity to make that decision when it should have happened way, way before it actually did.

The other would actually be suicide. That sort of goes hand in hand with depression as a safety factor.

CO-CHAIR FELDMAN: We're going to -- when Eleanor takes over we're going to be prioritizing across these measures, right. So, if you've got thoughts on this -- so if you've got thoughts and issues that really came out of your group that you want to be sure are really up there this is the time.

Chris, if there was anything particular on the detection side I think you mentioned.

MEMBER KAHLE-WROBLESKI: I would encourage the group to look at the pieces that we had created for detection and maybe pull a few of those out.

Again, I feel like it's great to have a conversation about quality indicators for dementia patients across all stages. But if they're never identified as a dementia patient it's not going to activate any of these supportive services and care services and coordination of care.

So inasmuch as we can label people appropriately so that they can become part of the system and have all of those services activated, to me that's the critical piece. I don't know if our group got all the right ones, or if the right concepts were there.

But I would encourage people to go and have a look and see which of those around the detection piece are maybe the most feasible or manageable right now that we could get started on and recommend moving forward toward.

And the other piece of it too, and I know the U.S. Preventive Task Force put out their recommendation that we shouldn't be doing any screening.

I would just say that we weren't talking about screening. We were talking about detection.

And the other piece of it for our

group too I think was around the evidence base. And there may not be an evidence base for all of the recommendations that we would make.

Although -- I won't speak for the group. I'm comfortable with that if it means that we have to develop that. But that's something we need to know as well.

So keep that in mind too. We may not have the evidence base now but if there are things that we need to do to create that then let's be aware of that as well.

CO-CHAIR FELDMAN: And I think implicit in the discussion of that group was that the evidence base, you know, we're not talking at this point about reducing -- certainly not reducing mortality. You know, we're really talking about effectiveness in terms of quality of life, advanced planning and that kind of thing. Katie.

MEMBER MASLOW: I just want to reinforce what Chris said. I think that because of the way that we talked about the hierarchical structure we didn't say as strongly as some of us would want to say the importance of detection.

So, none of this is going to happen without detection. And if you're in a system where patients or people come to you then you can give them good care without detection happening. But by and large you can't. So to me detection is the first and most important thing that needs to happen.

And the way that we were thinking about it was that if you are starting with people who you're envisioning are at risk for various reasons you have a better chance of detection.

CO-CHAIR FELDMAN: Murray.

MEMBER GROSSMAN: Our group also spent sometime discussing the issue of education and the way that that can occur at several levels, and the advantages of education.

And it's not just education in terms of having somebody delivering a competent message, but it's also being able to deliver that message in an effective way.

And it depends on the kind of thing that you want to communicate and the things that you want to communicate. You have to figure out what the costs are relative to the relative benefits.

And so some things we thought were effective to try to communicate broadly including making significant efforts to penetrate elements of the community where they don't have a lot of exposure to TV or to other kinds of media, to the internet, other things.

And I'm thinking here of issues related to very, very common healthcare risks or other kinds of demographic risks that can be the kind of things you have to worry about in terms of trying to prevent dementia from occurring. So, education becomes a very important kind of thing to talk about.

And education also plays an important role not simply in terms of helping to facilitate detection, but it's also important in terms of being able to convince individuals, family members, caregivers, folks in the community that there is some benefit to thinking about these kinds of risks. That it's not the no, let's take the approach that you can't do anything about it, but instead that we can do something. So it is worthwhile trying to do these detection efforts.

MEMBER COOLEY: This is Susan Cooley. Sorry just to butt in. I don't have a tent card to hold up.

I just wanted to mention also I seem lately to be hearing a lot more about risk factors and measurement of risk factors and then screening for risk factors and kind of moving further and further away from just recognizing overt signs and symptoms.

So I always want to put a plug in for the education of individuals, education of the public for individuals and families and providers on what are the signs and symptoms.

And then having them recognized, detected, the signs and symptoms detected. And then that prompts an evaluation.

So I agree that detection and evaluation is the beginning part before you can get into the rest of the measures related to good care.

But I personally would like to see more focus on the recognition of actual overt signs and symptoms because that seems to be missed quite a bit.

And not to take anything away from the developing area of risk factor identification and understanding, but risk factors is a very complicated area.

And I would not like to see a lot of effort put into that at the expense of measures that would help prompt people to actually recognize overt signs and symptoms. Put that plug in.

CO-CHAIR FELDMAN: Okay, Joan has her name raised. And I think Eleanor wanted to say something. And then I think the fateful time to vote will be upon us.

MEMBER TENO: One of the things to think about, everybody will agree that detection is important. But how do we measure it? You know, if they're not detecting it how do we get that denominator for that?

And then the other question is who's accountable? And that sort of puzzles me on how to go forward with a measure with those concerns.

CO-CHAIR FELDMAN: David, you're going to have the next to last word. And then Eleanor will have the last word.

MEMBER REUBEN: Actually, you'll be appreciative because it actually goes back to something you said earlier.

That whole idea is before we do this voting are there things that we can collapse so we have less voting to do. We have less to vote off the island.

And so, and I think there is. I think there's a fair number of things that we can -- so we have less to get rid of.

The second actually relates a little bit to what Joan was saying. There are two areas. One is importance. Actually, there's probably three areas.

One is importance. A second is how much evidence there is behind it which NQF will probably use the trump card anyhow.

And the third is practicality. You know, is it really feasible to do this. In other words, are you going to have a meaningful measure out of it in the long run.

And I think those things, they don't always jive. And so when we do this kind of dot exercise we really need to think about what the dot is -- which of those things is the dot measuring. So, that's it.

CO-CHAIR PERFETTO: Well, and David, my last comment is going to tie into what you just said in a couple of ways I think, maybe.

One of the things that I learned in the group exercise also was that we also need to be really clear about our definitions and what we're talking about.

And that there are terms that we throw around and we think everyone knows what we mean and then you realize, wait a minute, you and I were talking about completely different things.

So I think Lynn said long-term care and in my mind long-term care means nursing facility. Long-term care facility. And she was using the term in a completely different way.

And so I think one of the things that we really have to be careful of too in this conversation is not only how we're balancing out the criteria because some are going to pop up higher in other areas. And so that's a little bit hard to vote on.

But it's also whether or not we're

all clear that we're all talking about the same thing.

So with that said it's time for voting. We're going to give everyone four votes.

So, we're going to give you different colors and we're going to start at the top with the orange color. And it has the highest weight and the yellow has the lowest weight.

So you're going to vote for the four things across all of these that you think are your highest priority giving highest weight to orange, lowest weight to yellow. Now, that's the first assignment.

The other is that we know that you're going to complain and say some of this doesn't work because there are things on here that are so important within a category they can't be neglected.

So if you feel that way about something within a category you can take a blue and use a blue within a category to then

-- you don't have to, it's if you want to -- use a blue to give a vote to something that you think stands out in a category that it should not be missed. Okay?

CO-CHAIR FELDMAN: One blue?

CO-CHAIR PERFETTO: Well, I think people can take more than one blue if they like, but the blue is kind of -- you have to feel strongly about the blue. Okay?

MEMBER TENO: Other than blue are supposed to be for individual recommendations?

CO-CHAIR PERFETTO: You have four votes for anything from group 1, 2 and 3. We're going to get the highest four out of all of those.

MEMBER TENO: So what is the blue then?

CO-CHAIR PERFETTO: The blue is you feel strongly that something within a category, not across all of them, but something that's in detection is so important for detection that it needs recognition and that might get lost because we're voting across all of the categories.

MEMBER TENO: So we basically have five votes.

CO-CHAIR PERFETTO: You have five votes.

CO-CHAIR FELDMAN: Karen, I do think it would be useful for people who don't fully trust the democratic process for you and, you know, those of us who are the republicans with the small R, not the capital R, you know, and then those of us who are the democrats with the little D. Can you explain sort of what -- I know we're going to review all this tomorrow and so forth. But what happens after this? And particularly in light of the issue of things that may -- one may vote for them in one place so one wouldn't vote for them in a -- you know, the overlapping issues.

MS. JOHNSON: I think it's a little tricky because -- and tell me, Juliet, did you guys put on the sticky notes exactly as we had them?

CO-CHAIR PERFETTO: Everything that's been on the slides. Yes.

MS. JOHNSON: Okay. The tricky part is I think there was some overlap, right, across. So, I think the only thing that makes me nervous is that somebody will vote for it over here, but the same thing is over here. And it won't get voted on.

MEMBER BAYLIS: Can I make a suggestion?

MS. JOHNSON: Sure, I'm open.

MEMBER BAYLIS: Could we go through each item? Because I see numbers over there and then I see little lines. So I'm not sure which items are up for vote and how they're grouped.

So if we could, number one, address your first issue, go through each item and eliminate any duplicates, or anything that's related put them together into one item. That's the first thing.

And then the second thing is to take a different color marker and go A, B, C, D on each item, each grouping thing that we would be voting on.

MS. PRINS: So I think rationally it makes sense. I think from a time-wise I'm not sure how you want to do that.

CO-CHAIR PERFETTO: Well, I do think we can number things so that we know what is up for -- which lines are separate and distinct from one another. So we can number them.

But I think the other thing is after we've voted we can -- if it says, you know, shared decision-making on this one and we've got shared decision-making someplace else we'll pick it up and put it in there.

CO-CHAIR FELDMAN: And similarly, if it doesn't say shared decision-making on one of the others, and yet there was clearly discussion in the group, the fact that it got a lot of votes on there it seems to me would suggest that it would then be visited in light of at what points on the trajectory might shared decision-making be assessed.

So even though it doesn't necessarily appear in another one if it's a high priority item one would hope that we would then consider more than one point at which we would do that. Does that make sense?

MEMBER CARNAHAN: And these are healthcare system or healthcare provider quality metrics, right? So if we're seeing something that looks like it's more of a public health thing, for example, the awareness of the population, we should not maybe.

CO-CHAIR PERFETTO: Yes. I think our goal today was something that had to do with the patient with dementia and the caregiver. So, if something seems like it's maybe a little bit too broad then we probably would not -- don't vote for it.

CO-CHAIR FELDMAN: And I think that

almost inevitably will turn up tomorrow as one of the parking lot issues, how do we address those things. At least in the report.

MEMBER BAYLIS: If we talk about number one then we'll know what number one is.

CO-CHAIR FELDMAN: Oh, you didn't abandon your mike.

MEMBER GROSSMAN: So, I'm a little confused maybe about the process.

So, are we all kind of like voting now and then we're going to discuss tomorrow the ranking and then vote again? Which would be a nice thing to do.

CO-CHAIR PERFETTO: I think we're voting now and we're going to discuss again now. And if we have too much of a spread hopefully the discussion will help us get to a little bit of narrowing. Or maybe not. And so if we need to vote again today we can. We're just going to see how the voting and what the spread looks like once the voting takes place. That's been the plan. Correct, Karen?

MS. JOHNSON: Correct.

CO-CHAIR FELDMAN: And I don't think anyone would object to staying 15 minutes longer or whatever. We're a captive audience today.

MEMBER TENO: So can I ask about the motivation of getting down to five or whatever? This much smaller number. I mean, why? What if there were 20 or 25 measures here? What would be wrong with that?

CO-CHAIR PERFETTO: If there are 25 that's okay. It was just a matter of trying to get some priorities and to try to -- where there are opportunities to lump them, we'll lump.

But if there are -- we're not going to throw any of it away. None of it gets thrown away.

CO-CHAIR FELDMAN: And also think about it. There are so many people in the room that if we each vote on five things there are going to be concentrations of things and it's going to be on five measures. So I think this was just a vehicle for the discussion groups to, if I understood.

MEMBER BAYLIS: So you want to be able to see consensus, the degree of agreement? Like we all, you know, there was a large number of us had our dots on number nine. So that's like, you know, really consensus there.

CO-CHAIR PERFETTO: There's something going on there.

MEMBER TANGALOS: I have to kind of side with David on this. This is a nice framework that we've put together. And I'm not ready for Sophie's Choice. It just -- no, it actually doesn't seem that the winnowing process is necessary right now.

MEMBER JANICKI: What you might be suggesting is do a staff effort overnight to winnow it down to some broad categories and commonalities.

And going back to your concept of is it lumping or clustering?

MEMBER TENO: Lumping.

MEMBER JANICKI: Lumping. And then tomorrow we take a look at those lumps and see how much we want to weight them.

It just seems like it's so broad that even if you have this group you're not going to get too many items with the same hit.

CO-CHAIR PERFETTO: I think that's going to be the staff's call on how they want to manage that.

MS. JOHNSON: Yes. I'm just looking at group 1. Yes, that's a lot.

I mean, I think at the end of the day one of the things that we do want to be able to give HHS -- and I agree, we've done a lot of great work. So, by definition everything that we've discussed today is a priority to some extent.

But if HHS wants to write contracts

in the next couple of years for measure development and give some direction for measure development what kinds of directions should they give?

So, maybe 25 is where we land, but that might not be exactly where HHS needs to be. You know, they probably don't have the money for 25 contracts.

(Laughter)

MS. JOHNSON: So, you know, I know it's painful to try to winnow down but I think it might be worth the exercise.

And if we can't get there then we can't get there. And that's useful information as well.

MEMBER COOLEY: This is Susan Cooley. I just sent to Karen my four votes just assuming that we do have to have four.

I agree it's difficult and you may end up having a much longer list with the number of votes of each. And you have some cutoff at some point. And it may be beyond four.

But at any rate I just sent a four and then some blues, standout items in addition to the four.

CO-CHAIR PERFETTO: Thank you, Susan. Ryan, you were next.

MEMBER CARNAHAN: I was just going to note that some of these may have quality metrics too. And so we may end up, you know, if person-centeredness is something that's really been addressed we may end up picking that because we think it's important but something else already exists.

And then I don't know exactly how this is going to all fall out in the end but we might want to consider that tomorrow.

CO-CHAIR PERFETTO: Joan.

MEMBER TENO: I actually think there are some things that are up on the list which probably need to come off the list.

So, for example, educate healthcare workforce. That's a wonderful goal, it's something we all should do, but I don't know if I would make that a quality metric.

CO-CHAIR PERFETTO: I guess I would say that -- want to just turn it around and say what if we rephrased it and it said the dementia knowledge of the healthcare workforce. Is that?

MEMBER TANGALOS: I've got that same problem too. Because I've got to go back to the Alzheimer's plan. And a lot of these things that we've got, there's capacity-building in them. There's a lot of capacity-building.

But I'm not convinced that that's our task here. I mean, I'm really not sure it is.

MEMBER KAHLE-WROBLESKI: Eleanor, can I? And we had a brief conversation about this in our group. And I think the importance of having that up was more for parking lot than this group necessarily solving it, right?

So, I would agree that the broad educational kinds of efforts probably don't lend themselves to quality but in the end are going to impact that. And so we can put them in a parking lot and not have that be part of the vote.

CO-CHAIR PERFETTO: Do we want to go through an exercise of putting -- going through these and saying what belongs in the parking lot? Before voting takes place.

MEMBER BAYLIS: Then don't vote for it.

CO-CHAIR PERFETTO: I agree, but it might make voting easier if we're voting on less than 30.

MEMBER BAYLIS: I have another suggestion if I could. I usually use a rule of thumb. You get one-third. Your number of votes is one-third of the list. So that would be 10 votes. No? That's generally, that's pretty typical.

CO-CHAIR PERFETTO: But I was -- does anyone feel strongly about eliminating things off this list before we start? Or not? I'm not hearing or seeing --

MEMBER REUBEN: I mean, I'm okay with it because I haven't heard that anything that doesn't get voted is eliminated. It's just that we now see where our initial ranking went. And so I'm comfortable.

CO-CHAIR PERFETTO: Hearing that the intent of some of these groups was not -- that these would be parking lot items. So, why would we vote on them if that was the group's intent? Should we do that, or does it matter at this point?

I don't see any enthusiasm. It's late in the day and everybody just wants to get out of here.

All right, then. Here's your opportunity to get out of here. Take your stickers and vote.

(Voting)

MS. JOHNSON: And we have a little bit of break built in so feel free to do a break, bio break or have a snack. There's still cake left.

MEMBER COOLEY: Do you know when you're going to resume?

MS. JOHNSON: What do you think, Eleanor?

MEMBER COOLEY: I assume that they're voting?

CO-CHAIR PERFETTO: Yes, everyone's voting right now and there's a little time built into the schedule for everyone to have a little break if they need it right now.

We do have someone who will be joining us on the telephone for public comment at 5:15 and we're trying to get in touch with him to see if he might be able to join a little bit earlier.

But if we take a little bit of a break now and come back, have a little discussion about where our dots are falling that should tie into the 5:15 public comment.

MEMBER COOLEY: And Karen got my dots? This is Susan. Karen got my votes?

MS. JOHNSON: Thanks for reminding me though. I need to put those dots up.

CO-CHAIR PERFETTO: Susan, your dots have been put up.

MEMBER COOLEY: Oh, thank you. Appreciate it. I may have to leave shortly before 5:30 but I'll hang in as long as I can.

CO-CHAIR PERFETTO: There are blue dots here if anybody wants to use the blues. If you feel very strongly that something is very important to a particular group, that it stay there, then use a blue dot.

MS. JOHNSON: You can consider this break. We're just talking amongst ourselves.

MEMBER COOLEY: Thank you.

(Whereupon, the foregoing matter went off the record at 4:50 p.m. and went back on the record at 4:57 p.m.)

CO-CHAIR PERFETTO: Okay. So we were just discussing that we do see clustering where people did pick -- a lot of people picked some favorites. And there are a number of places where there can be some consolidation.

So the staff is going to take a look at this tonight and they're going to present the results to us tomorrow with some lumping together of some of the things that we see up here grouped and then with the counts on what got the heavier voting.

But I think it looks pretty much like we've got a lot of grouping so we're not in too bad of shape. I think we can manage this.

We -- did you have anything else you wanted to cover while we wait for George?

MS. JOHNSON: We didn't, other than a couple of these things over here it would be nice to hear from you in terms of any additional parking lot issues that we want to cover tomorrow.

We have a list that we're pretty sure we want to talk through but maybe now is the time to make sure that we hear from you about your parking lot issues. If you have any.

MEMBER TANGALOS: We've talked a little bit about population management. I think it's a little closer to our task than capacity-building.

But again, it's a new concept that's out there. It's hit at in a bunch of different places.

But again, if we're going stay, or try to stay ahead of the curve, I mean population management is what ACOs are talking about, what we in general are talking about.

And it's that link that we struggle with between the clinical systems and the community systems. So, anything that we can do to further identify how to manage a population probably does a better job of linking what is now de-linked from the healthcare system and the community resource base.

CO-CHAIR PERFETTO: Bill?

MEMBER STAPLES: Yes, I just wanted to make sure that Eric's talk about safety was included in the parking lot issue. I think that's big. And I would have liked to have had it to put a dot on today.

MEMBER HASHMI: Point of clarification, Eric. When you say population management you're not talking about population health?

MEMBER TANGALOS: It can be part of it. But again, I think as we think about what to do with a population as health plans start to think about what to do with populations.

I know our planning actually really does involve community engagement, much more than ever before. And if that word "community engagement" is the word you want to make the link, that's fine.

But that is the interface. That is where the medical piece becomes part of the community piece and where things get done.

MEMBER HASHMI: So what you're talking about is social determinants that contribute to the overall health status.

MEMBER TANGALOS: Part of it. That's just part of it.

But I mean, you could go back to the safety issue. I mean, we know this from the previous White House Conference on Aging. We have the most terrible public transportation system in the world. So, for a healthy population it needs sidewalks and public transit.

CO-CHAIR PERFETTO: Other parking lot issues?

MEMBER TENO: Yes. I just, I want to re-raise that issue about the valence and the evidence and the practicality. I think those are issues that are too easy to dismiss. I think they're too easy to dismiss. And I think I want to make sure that they stay on the table.

MEMBER GROSSMAN: So, this is where our educational issues belong, the ones from the group 1. Where you're talking about education in terms of the population being able to recognize at large what kinds of things represent risk factors. Educating health workers. And so worry about falls as possibly an early marker for dementia, that kind of thing.

CO-CHAIR PERFETTO: Do we have a list of some of the other things that we've been collecting from earlier today? That we could just read off to be sure that we've covered everything. Chris?

MEMBER KAHLE-WROBLESKI: For the parking lot I think too we had brought this up. Part of it was education, but -- and I'm not sure if any of these on the list would fall under that.

But if there were some -- if there are any quality indicators that maybe aren't at a physician or healthcare system level, that are more in social care system level, to make sure that we're pulling those out.

And if it's not the purview of this group that we make sure that it's channeled to the right group to address those.

CO-CHAIR PERFETTO: That is something that we would use to help instruct the staff tonight and kind of lump those together in a separate place so that we can have some discussion about those separately tomorrow, if something is more on that population community level versus our charge of patient and caregiver.

CO-CHAIR FELDMAN: I was just taking notes during the discussion. We had discussion of the numerator-denominator issues.

We had discussion of personalized measures and creating some kind of a composite of goals on the one hand and outcomes on the other.

I think -- well, we talked about a family-centered health assessment but I think that's on the list.

Coordination between the healthcare system and the long-term services and support system. Which goes way, way beyond the 5 percent in nursing homes.

Let's see what else. Those were the -- and the education one.

MS. MYERS: Other things that I've noted just throughout the day is the issue around the proxy and who's reporting. The individualized measure approach. That was already mentioned. And accommodations for people with dementia, the structural measures.

CO-CHAIR PERFETTO: Ryan.

MEMBER CARNAHAN: I don't know if it fits here but the consideration of existing measures that are particularly important for people with dementia.

CO-CHAIR PERFETTO: And keep in mind, our charge is not to come up with a new list. It's to include all of those kinds of things, but start fresh with a blank piece of paper and not confine ourselves to existing or non-existing. Katie?

MEMBER MASLOW: I think that the

education one, Murray's education, actually should be connected to the first one. So that we're talking about clinical and community systems link, and that the end is basically going the other way.

So if you start in the community as we discussed it, creating greater awareness and knowledge about cognitive impairment and risk factors and so on. And then you go to clinical. So it's the other end. Maybe I'm being incoherent.

But anyway, I think that it's connected there, that there's a community side, sort of a public health community side, there's clinical and then there's community agencies.

MEMBER CARNAHAN: I don't know that the providers can be ignored in the education piece though. I mean, just knowing how we've tried to promote better delirium care at our hospital and people still just don't get it in a lot of cases. Even though they're getting screened, they're getting identified, the providers don't know what to do.

CO-CHAIR FELDMAN: Mark mentioned the stroke awareness campaign which I think is a community effort but it's also pervaded the provider community as well. And so we had some discussion of that.

CO-CHAIR PERFETTO: We only have to stall for about six more minutes.

Well, do you want to talk about that? It was someone that we had invited to come and speak today who wasn't able to come. And so we offered him the opportunity to give a few comments during the public comment period.

So I don't think that it's because he's commenting because he has anything controversial to say. It was because he wasn't able to make it.

MEMBER HASHMI: That's what I was trying to figure out, if he was an important stakeholder from a perspective. Thank you.

MS. MYERS: I can comment about

dinner tonight.

CO-CHAIR PERFETTO: Oh, that's a great idea.

MS. MYERS: So, there's dinner reservations at 6 o'clock at a restaurant around the street called Mio. It's 1100 Vermont Avenue. We can provide you exact directions. But it's one block over. And we hear it's very good so you all are invited to that tonight. At 6 o'clock, so 40 minutes.

MS. JOHNSON: And the purpose of that is just to give you a little bit of more informal interaction with each other if you care to do that. Some committees really like it so we wanted to offer that to you.

Juliet, right now it's under your name, is that right?

MS. FELDMAN: It's under my name.

MS. JOHNSON: It's under Taylor's name. It's Taylor Myers.

MEMBER REUBEN: Just while we have a couple of minutes I've been thinking all day.

Some of what Eric said this morning about NAPA. HCAHPS has been mentioned several times. And I think CG-CAHPS I would throw into the same boat.

And somehow figuring out to the extent that those exist there's some overlap with what we're trying to do. And so I think thinking about how those things that are already out there can potentially be used to further this would also be pretty helpful.

CO-CHAIR PERFETTO: Harmonization. Okay, thank you.

MEMBER TENO: You might want to see how often dementia patients are excluded in the original CAHPS survey and health plans. It might be interesting to tell you how much of a population you already have.

CO-CHAIR PERFETTO: D.E.B., is that something that you'd be able to help with?

MS. POTTER: Yes. It's also possible to sort of look at what percent of the hospital population among age groups get discharged to nursing home and then overlay that on the CAHPS and saying well, among the population 80 and above we're mixing X percent. You know, you can look at it that way also.

MS. JOHNSON: So, a couple of other things that we had on our parking lot issue for tomorrow, just to plant this in your mind. We've already talked about it quite a bit, but it's anything about assessing quality through the lens of dementia.

So, again, I'm not sure if we quite got it on these dots or not, but what might that look like, what kind of recommendations might come out of that.

And another one that was on the list. I think we're talking a lot about evidence now and feasibility now and that sort of thing. But what about five years from now if the science changes? What do we need to be thinking about?

We obviously don't have a crystal

ball. We can't know for sure, but maybe there's just a little bit of insight that you guys can give us. So we want you to touch on that a little bit tomorrow as well.

CO-CHAIR FELDMAN: Is the idea that additional recommendations would grow out of our discussion parking lot issues?

MS. JOHNSON: I think they could. You know, and D.E.B., you might could help more with this. But I would imagine HHS might be interested in just ideas for things that you may want to fund eventually.

MS. POTTER: HHS is interested in what the stakeholders have to say. So if you all think that something is really important and that's not bubbling up then that should be included in the report.

That's the purpose of all of this is to hear from the stakeholders. So there's not a right or a wrong.

CO-CHAIR PERFETTO: We also wanted to give an opportunity to any of the people still left behind us over here if there were any comments or any issues that anyone wanted to raise.

MS. JOHNSON: So I feel bad that we're kind of filling in time. George, are you on the line?

MR. VRADENBURG: I am.

CO-CHAIR PERFETTO: Great, well we've been waiting for you. We've been stalling for a few minutes while we've been waiting.

MR. VRADENBURG: Oh no, I apologize. I had it at 5:15.

CO-CHAIR PERFETTO: Great. So let me introduce George Vradenburg who is going to give us a few comments. We had asked George if he would be able to come today to join us and he was not able to.

George is a tremendous advocate in Alzheimer's disease and has been very active in this area for a number of years. And leads the Us Against Alzheimer's group as well as other initiatives. So we thought it would be nice to have someone like George give us some of his thoughts on the direction for quality and his experiences.

So George, I'm going to turn it over to you.

MR. VRADENBURG: Well, thank you very much. Was that Eleanor?

CO-CHAIR PERFETTO: It is.

MR. VRADENBURG: I want to say how impressed I've been with Eleanor's leadership in this area for now some period of time in getting this work started, and getting it focused, and getting it so comprehensive. It's really a testimony to the importance of leadership.

I want to thank you for taking this call. I know how important this work is. In my work where I'm on the Commission on Long-term Care one of the things, one of the critical elements that we to a person thought was vitally important was the development of some common assessment tools and an assessment system across care settings, across the stage of the disease, that could be implemented by a workforce with multiple skill sets.

That was portable with the patient so that as the patient moved through acute, post-acute, home, or residential settings that the assessment moved with the patient.

That it was patient-centric and family-centric. That it included the caregivers and the team that was charged with the care for the individual no matter what the setting.

And so we advocated that and it was part of our Commission on Long-term Care work that we thought that this is vitally important. So that the work that you're doing I know from experience across a number of these efforts how important it is.

And really only three quick points here. I do think it is -- this is obviously my personal point of view coming from sort of a patient advocate's or family advocate's perspective.

But I think it is important that we get clear what the objectives are of creating a national quality system, assessment system.

It is not just a body of definitions or professional guidance. It is a potential tool to actually take a system that exists today with whatever assessment across all those things are in terms of the quality of care being given to individuals and raise it through time.

That is to say, to be able to assess what the quality of care being delivered to the patient populations we're concerned about. And then to say through time what are the -- how is that system improving to improve the quality of care as well as hopefully mitigate the cost increase.

That means that the assessment system has to have certain standards inside of it, data-recording standards. It has to have a certain format to it that can be used in different care settings and by different kinds of professionals.

It has to be capable of being -- the data in those reports and assessments has to be accessible in some national way.

And the people that are reporting, we have to be able to compare the performance of various elements in the system through time, and across settings, and across stages of the disease.

And therefore be able to hold ourselves accountable for assuring through time that the level of care that is occurring throughout society is improving through time. So point one, that we need some vision and objectives for what we're trying to do with the quality system.

The second is implementation. I've heard people say that a vision without action is a hallucination. So I do think we need a system that can be implemented.

And I think that comes in two

dimensions. One is what I just said, that is that we have a system with standardization and reportability in it across these various dimensions that I mentioned.

But it also has to do with who has to change their behavior in order to get that system actually put into place.

One of the things that comes across pretty consistently inside the work that I do with the NAPA Advisory Council on Alzheimer's as well as the Commission on Long-term Care is that the system is very, very complex with multiple actors.

It has traditionally been viewed as a medical system when we're now talking about medical and social services which have never been particularly well connected.

And so figuring out who it is that has to change what in order to create assessment tools that will be used by different institutions and different professional categories, and actually getting it implemented. Or at least beginning to describe and characterize the pathways to getting it implemented I think is an important element of trying to think through what we're trying to achieve here.

Because a system that can't be implemented and can't have consistent reporting can't be held -- no one can be held accountable and we won't get movement through time in terms of the quality of care.

And the last point I'll make is that the problem you're grappling with is occurring -- is a problem being grappled with in other countries in the world, particularly industrialized countries now but increasingly in low- and middle-income countries. Because dementia is now not only global, two-thirds of the cases are in low- and middle-income countries.

So finding a system that can be easily described, easily characterized and where one can understand where the levers of change can be and where it can be implemented and implemented at relatively low cost is going to be important to the world.

And so America can both lead here if we can find a way to characterize, describe the system and its implementation with clarity and simplicity.

But it also can learn from what's going on in other industrialized nations, particularly those that have national health systems, whether it be the European system or the Asian systems, because they have fewer levers to turn, but they also have the same objectives.

What is the diagnosis rate for those that are at risk or have the disease. What is the most diagnostic pathway to treatment and to care. Are care systems adequately documented and implemented. And are patients receiving the care that they need and deserve and want, and customized and personalized in a way that makes sense for them. And is that improving the outcomes of the people that we're all trying to serve.

So that is occurring in Europe now. It's also occurring in major Asian countries that are indeed grappling with the problem. And so we can both learn and we can also teach.

If we are able to characterize our system in a way that is not complex and not difficult to understand and if it is patient-centric rather than system-centric so that in fact it can be well understood by those that we're trying to serve.

So, I thank you for the opportunity to offer just a few comments. I hope that they're relevant. I do not have the expertise that you all have but I am relying very much on your expertise to hopefully develop a system that is -- that can over time both measure and improve the care that are given to people with dementia.

CO-CHAIR PERFETTO: George, do you

have a minute for any questions if anyone has a question for you?

MR. VRADENBURG: Sure.

CO-CHAIR PERFETTO: Does anyone have any questions? You know what, I think we wore everyone out today, George. They're all looking very tired.

(Laughter)

MR. VRADENBURG: There are a series of convenings that are going on now in Europe and then will occur in the United States this fall and then Japan later in the year all of which are going to try to develop this sort of set of ways to measure the quality of care that's delivered and received both by the person with dementia as well as the caregiver.

So this is going to be a year of learning to say the least on these care systems and to determine where there are good ideas that can be translated across national boundaries and be able to implement some of the commitments that the G8 nations have made and now the OECD and 34 nations to deal with this problem both as a problem of research and new medicine development as well as care.

CO-CHAIR PERFETTO: George, thank you very much for joining us. And hopefully the report that will come out of this effort will be very useful to those other initiatives that are going on.

MR. VRADENBURG: Terrific. Thank you very much.

CO-CHAIR PERFETTO: Thanks. Bye.

MR. VRADENBURG: Bye.

MS. MYERS: Operator, can we open the line for any other public comments?

OPERATOR: At this time if you have a comment please press *1 on your telephone. There are no comments at this time.

MS. MYERS: Thank you.

MS. JOHNSON: Okay, I think we're done for the day. So, go have some supper and relax and we'll see you bright and early tomorrow. I think we're starting at 8, is that right?

MS. FELDMAN: Yes. The meeting will start at 8. Breakfast is at 7:30. Please do not come before 7:30 though because the building will not be open. So, 7:30.

MEMBER COOLEY: Be back with you then. Bye bye.

MS. FELDMAN: Thank you.

(Whereupon, the foregoing matter went off the record at 5:24 p.m.)

C E R T I F I C A T E

This is to certify that the foregoing transcript

In the matter of: Alzheimer's Disease and
Related Dementias Committee

Before: NQF

Date: 06-02-14

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