NATIONAL QUALITY FORUM

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ALZHEIMER'S DISEASE AND RELATED DEMENTIAS COMMITTEE

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TUESDAY
JUNE 3, 2014

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The Committee met at the National Quality Forum, 9th Floor Conference Room, 1030 15th Street, N.W., Washington, D.C., at 8:00 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
TAYLOR MYERS
WENDY PRINS

ALSO PRESENT:

CILLE KENNEDY
SHARI LING
D.E.B. POTTER
JANE TILLY

* present by teleconference

C-O-N-T-E-N-T-S

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

8:04 a.m.

CO-CHAIR PERFETTO: Okay. Good morning, everyone. Susan, are you with us? Okay. The line is open. So, we'll hear her join, I think, when she comes on.

MEMBER COOLEY: I'm here.

CO-CHAIR PERFETTO: Oh, she's here. Oh, good. Thank you. Good morning.

MEMBER COOLEY: Good morning.

CO-CHAIR PERFETTO: We are going to get started. Actually, it says we're not supposed to start until 8:15. Karen, we have you as doing an 8 o'clock.

MS. JOHNSON: So, good morning, everybody. Hopefully, you guys had a great night and didn't dream about dots like I think I did. And, hopefully, you're ready to go today. So, we want to just review the agenda. And, basically, as you know, we got through what we were hoping to get through yesterday.

So, we actually did come to some

consensus about some top priorities. So, what we want to do this morning is just go into detail on those priorities and try to flesh some of those out a little bit. So, I'll show you or we'll show you in, in a few minutes, what you can see from those dots.

And, then, I have some clarifying questions that I think would be useful to discuss to kind of get a little bit more fine tuning of those. But the 8:15 session, that's where we also want to talk about some of those issues from the parking lot that we talked about yesterday.

So, what do you want do with safety, for example? Penny is saying, hey, we already had that scheduled for a little bit later. But I think what it is is some of the parking lot issues came up and we'll just basically be doing those throughout the rest of the day.

We want to clarify a few things, in terms of population health and those sort of things. As a matter of fact, don't let me forget to come back to that --- with D.E.B. Yes. D.E.B. was going to help us with that.

But I may get started, in just a few. Just in case she's running a little bit late. So, basically, the rest of the day is just going to be continuing to talk through some of our recommendations.

We started talking a little bit about some of the methodological challenges and, you know, how do you find those denominators and the messiness of things. And I think we want to talk about that in a little bit more detail today.

We also, for me, not for several of you but for me, the idea of the dementia-capable communities and that sort of thing and that linkage between the community and the medical system, I think we can talk about that a little bit more and make sure that we and I know where you are thinking of going in that direction.

We will have a working lunch and, with that, we will do a bit of a round robin reflections and I'm still debating what I would ask you to reflect on. So, that'll be your surprise for a little bit later.

So, it could be last word or I actually may ask you to think about how you think this work is going to really impact the field, which is what we're hoping. This is not just an academic exercise.

So, with that, I think the one thing that I do want to clarify that we got off on a little bit of the wrong foot yesterday and that is, basically, thinking about population-based measures.

And I think, Ryan, we weren't sure afterwards, just the way you phrased the question and hearing some feedback from some of the small breakout groups, did you guys feel that thinking about a population-based measure was out-of-scope for you? And the answer to that is no.

So, definitely, if some of these things that you've talked about really are or may be better done where a population or a larger entity than just a clinician or even a facility or an ACO should have that accountability, then that is perfectly fine. And, as a matter of fact, I think that would be something quite useful that might come out of your deliberations.

So, Ryan is looking a little puzzled. So, I don't think I quite explained this a little bit. So, maybe we can just chat about the population health just a little bit.

MEMBER CARNAHAN: Yes. I was just kind of thinking in terms of feasibility, if from a public health perspective you want to educate the population about the disease and risk factors and then how do you evaluate it, who do you try to reach to try to evaluate it and will they be the people who have been reached by those messages? And, you know, there's just some difficulty there.

MS. JOHNSON: Yes. With those kind of measures, it very well could be. One of the things that came up, and we'll talk about it, one of the things that came up is, you know, one of your high-priority items was that dementia-capable idea. And that may be one, in particular, because that's multisystem, right?

So, that one is perhaps one that would be a population-based thing. So, again, I don't want to put words in your mouth and write this for you. So, maybe, everything that we would like to do at a population level isn't feasible now. But maybe some things are and maybe some things have to be thought of at that level.

CO-CHAIR PERFETTO: And D.E.B. felt strongly that we not put it aside and she said it's okay if it's a little bit ambitious right now. That's okay. But, in terms of what HHS is looking for, that is part of what they're looking for. So, she asked us not to put those aside.

CO-CHAIR FELDMAN: She actually emphasized that.

CO-CHAIR PERFETTO: Yes.

MEMBER CARNAHAN: So, thinking more in terms of structure of communities and available resources in communities, is that the perspective?

CO-CHAIR PERFETTO: Yes. She said don't take it off the table. So, if we feel strongly about something, keep it in there even though, to your point, it may be an ambitious measure at this point or ambitious goal at this point.

MEMBER COOLEY: This is Susan Cooley. I just wanted to mention this was discussed at the last HHS Alzheimer's Advisory Council meeting. And I know that maybe some people in the room, Jane Tilly, others, Katie Maslow was probably at that meeting, others who will remember.

The example that they gave, they

talked a lot about dementia-capable communities and the work in the UK and I don't have the materials from the Advisory Council meeting in front of me. But one of the examples that they gave was a speaker from Minnesota and they have built on the UK work about dementia-capable communities.

And Minnesota has a website that's actonald.org. I'm looking at it now. And, so, their whole thing is about developing dementia-capable communities. I don't know that they have any performance measures, any evaluations built-in. I haven't really explored their website.

But those who were at the Advisory Council meeting will know that the speaker was very dynamic and everyone was very fired up and excited about this as a U.S. example of really working on communities, everyone being a neighbor.

I mean different catchphrases that related to the awareness and capability of local community organizations to help individuals with dementia. So, actonald.org is Minnesota's website for their approach to that.

CO-CHAIR PERFETTO: Thank you, Susan. Karen?

MS. JOHNSON: Yes. Joan, you have your card up.

MEMBER TENO: You know, I think we need to be strategic and you need to think about the measures, about who's accountable. Okay? So, you know, if you want to do population-based measures, you could create a state measure. Okay? You could create a health system measure.

And you have to also think about the fact that there is just not money out there right now. So, you have to figure out could you piggyback something onto the BRFSS? You know, you have to be opportunistic.

It's great to think, you know, this wonderful pie in the sky. But the reality is, you know, it took me since 1997 to get a survey committed for hospice to measure the quality of care, despite all the problems.

And, so, you know, I think you really have to be strategic and persistent and think about how a small step can have a huge impact.

CO-CHAIR FELDMAN: I see D.E.B. just arrived but you're in the middle of the conversation. So, correct me. I mean I thought one of the things that you said to us in an aside yesterday afternoon was that, for example, communities are letting contracts for block grants, for example.

And there's also a lot of innovation money and dual eligible money coming from the feds and the states. And there are contracts with requirements and those are other ways that certain kinds of measures get built in. So, maybe D.E.B. can elaborate.

MS. POTTER: Yes. The National

Quality Strategy includes healthy people and healthy communities as one of its goals. And, while we're used to thinking about quality measures in terms of accountable entities, health plans or providers, if our goal is to have a healthier population or improve the well-being of the population, then we need to also think about other types of entities.

And, so, Joan mentioned states. If you think about the state aging agencies which get block grant money, one could think about a statewide measure. One could think about a measure that looked at counties that lined up with local agency on aging.

Providers can't direct people to community resources if someone in the community isn't going in the other direction. And, so, thinking about those types of measures, which some people call population measures, some people call area measures, some people call public health measures is another type of measure that you could be thinking about.

MS. JOHNSON: And, as a matter of fact, one of the questions that we will be talking about just in a few minutes is who would you suggest would be the accountable entity? So, you're right on track of what I was thinking that we wanted to try to pin down.

MEMBER TENO: If I was going to be strategic, the biggest threat to the quality of care for people with advanced or severe dementia is these new programs, which are blending both sources.

If we don't have transparency, you know, I don't know how many of you read the headlines for the Wall Street Journal. It's right there front and center. The VA was collecting its data, wasn't publicly reporting it. And the rates of differences, in infections, if I was a consumer or a child of a vet I would be appalled by this.

So, I think, you know, there's

really an urgency with transforming our healthcare system, changing the incentives from a fee-for-service system to, hopefully, incentivizing quality. But part of that is we're trying to achieve efficiency and this is a vulnerable population.

Already, we have really good evidence that fee-for-service medicine has not served this population well. So, you know, I think, you know, as we go forward with these innovations and I support going forward with the innovations, but we have to have transparency that is based on shared decision making. It's based on information about prognosis.

If we don't have that, we're going to have such a backlash. You know, just look at what happened in the UK with the Liverpool Pathway. You know, in the Liverpool Pathway, they paid people to put people in the Liverpool Pathway by actively dying. And it turns out, hospitals in UK were putting people on the Pathway without consent and that was a huge scandal.

Right now, as a result of that scandal, nearly every death in the U.S. by the coroner's office is being treated like it was a homicide. You know, essentially, they're investigating every death now.

So, you know, I think, if we don't urgently start adopting transparency and have good measures, a lot of healthcare reform is going to blow up in our face because there will be some kind of scandal because of some set of providers doing, you know, unfortunately what some, you know, a small percentage of providers do, maximize their profit at the cost of quality of care and compassion.

MEMBER HASHMI: Just a quick point. By no means am I an expert here. But, you know, I heard about transparency. I heard about the payment incentives need to change or need our changing. And, then, not to put away the, you know, sort of put on the parking lot the community or the social metrics or measures that are important, that are going to drive some of the changes.

The other advantage that we have, at this point in time, that we didn't have let's say 20 years ago is the emerging science of social networks and the emerging science or even established science of the behavioral economics.

And, if there are ways in which community behavior or group behavior can be modified by studying the behavioral economic signs or even just simple things like loss aversion or choice architecture, if we could build that in to drive group behavior, I think it would be worth studying and it would innovative.

MS. JOHNSON: You go.

MEMBER TANGALOS: Last night, when we were just waiting around for George, I was thinking about what would I do as a consumer advocate? And, so, this discussion is moving in that direction. And, as a consumer advocate, I'd be very upset about every facility out there that's assisted living that plasters a name on it that says, this is memory care.

That preys on the consumer I think more than anything else. There are no deliverables with a facility being able to put the label "memory care" on their unit. And I think, since we're thinking global now or thinking about states, we're thinking about populations. We're thinking about the consumer.

This is a stretch for even NQF. But I really think that we do the public an incredible disservice preying on them with that concept of memory care, when it has no meaning. It has no deliverables. It means something, as an advertising ploy, but it has absolutely no deliverables.

MEMBER MASLOW: This will be

another stretch for NQF and probably doesn't go for NQF. But I was thinking, in the discussion about states, cities, AAAs, that I wonder if somebody could pay for a pulling together of what those options are. There are a lot of options now.

So, at the NAPA meeting we heard not just about Minnesota. And Minnesota is looking for measures. Remember when we were doing "add me"? Minnesota wasn't looking for quality measures. The Legislature was looking.

San Francisco presented the dual-eligibles in California. That project's looking for measures, right? I think that the AAAs, AARP is doing its state measures. You know, what makes a state capable, whether there could be a dementia measure eventually? But pulling together those possibilities I think would help everyone think about what might be there.

And, if those entities knew there

was a list, maybe they would look at it when they are thinking about this. So, that's not probably an NQF task, but it might be a NAPA task. I don't now. What do you think, D.E.B.? Do you think it makes sense?

MS. POTTER: I didn't hear everything that you said.

MEMBER MASLOW: Oh, I'm sorry.

MS. POTTER: It was clear you put something on my plate.

MEMBER MASLOW: I'm sorry.

MS. POTTER: I'm not sure if it's a NAPA task or an NQF task. I do know that this group is part of the legislation that's actually in the ACA that calls for stakeholders, through the consensus-based entity, to report to the department. So, you all have a legal mechanism just as NAPA does.

So, from inside the Department, you never know how holes are going to get plugged. And it may not line up at all with what you think on the outside. But that's just the way large organizations work, whether they're a hospital or the Department of Health and Human Services.

So, I can follow up more with you, Katie, and then answer the question after the break. How about that?

MEMBER MASLOW: Yes. I just think there are more places right now that are looking for measures than there were five years ago.

MS. POTTER: Sure.

MEMBER MASLOW: And more entities trying to do dementia-capable care.

CO-CHAIR PERFETTO: D.E.B., can I ask a question? I think what I heard you saying is that, as part of our report, we could say that it is an imperative that a focus be put on the development of, or adaptation of something that's existing, so that it could be in some way applied at a community level.

And community could be defined in

the way that the entity needs to define itself, as long as it has a mechanism for capturing a numerator and a denominator. And we can put that in our report, that this an imperative, that we must take a look at the landscape to see what's available and if there is something's there that could be adapted.

And, if there isn't anything, something must be developed because this is a national crisis.

MS. POTTER: There are quality measures out there and some of which already have NQF endorsement that uses the denominator of a population. So, measures of potentially-avoidable hospitalizations that are for a county, for example, have, in the denominator, some measure of the population, whether it's the Medicaid population or the U.S. population.

So, it is possible to take the denominator from survey data or census data and, then, have something else at the numerator. That's one way to go about doing it.

MEMBER MASLOW: We also have the two healthy people, so we have potentially-preventable hospitalizations as one and people who know that they have a diagnosis as the other. So, those are there.

MEMBER GROSSMAN: So, this is entirely aspirational and can't be attained in a practical sense. But, from my perspective, if we want a healthy population, want to prevent dementia, we have to think of this issue as being a life span issue, not just an issue related to aging.

And, from that perspective, I think of all of the educational things that we can do at several different levels that would help us over the course of a life span minimize the risk of the future development of dementia. This is an issue that came up in our small group yesterday afternoon and is part of an issue related to education.

So, issues such as minimizing the risk of developing small vascular ischemic disease, which are things like hypertension and cholesterolemia, diabetes, these are issues that I think are educational in nature to the extent that the accumulation of these risk factors can result in mini strokes and, therefore, can result in vascular dementia.

We want to start educating people early on in a variety of ways using TV to advertise things like healthy diets and being in touch, making sure we monitor hypertension and hypercholesterolemia and diabetes. These are also issues that are end points that can be monitored.

We can monitor blood pressure on a publish-minded basis and just like we can monitor admission to hospitals or reduction of admission to hospitals for certain kinds of things that can eventually lead to dementia.

So, I view, again, an entirely aspirational perspective, that you should be starting early and our goals should be not next year but 20 years from now. Trying to convince people of that, well, we have to worry about our progress over quarters rather than over years or decades, is very, very difficult. It's a real challenge and it involves reorienting our priorities.

But I think it would be an important kind of thing, if we really want to make progress over the long term.

CO-CHAIR PERFETTO: Okay. Well, thank you for that discussion. And, D.E.B., thank you for raising the issues that we could have a good discussion about that and get back on track.

So, why don't I jump into a review of the prioritization from yesterday. We don't have handouts for you, but everything has been consolidated into some slides that we're going to go through.

And what we wanted to do was just review where the voting fell yesterday. And, so, these are the priorities that we came up with, by category. And the numbers that are on the slide tell you the weighted number of votes. So, this is counting, not just the sticker being there but the color of the sticker.

So, for persons with dementia, detection should lead to diagnostic evaluation. Diagnostic evaluation is intentional and results in a diagnosis, occurs in a reasonable time, is documented, core dementia work-up, hospitalization, transitions of care including long-term care facilities. Those are the top under persons with dementia.

For the family caregiver, support of the caregiver. And it was described as a composite that had different pieces to it: assessment, communication with the family, training, responsive to needs, listens to you and, then, advocacy.

And, then, for both the person with dementia and the family caregiver, a dementia-capable healthcare system. And you'll notice that this got the most weighted votes out of anything, 31 there. And, then, shared decision making and that included advanced care planning.

Again, we discussed a composite that could include prognosis, treatment options and education, caregiver participatory decision making and, for the person with dementia, assessing personal treatment goals. So, does anyone find any of that shocking in any way? Razia?

MEMBER HASHMI: I'm surprised about core dementia work-up. The reason being that, you know, core dementia work-up, in my mind, implies that they are already at a clinician and that they are receiving the prescribed work-up.

I think the gap, in my mind in terms of a performance measure and where we don't do so well, is early diagnosis and early detection. So, that's just my impression.

Once they add a clinician who even has some semblance of an understanding of what needs to be done, a work-up ensues. Either they get referred or they are evaluated. So, that's just my surprise.

CO-CHAIR PERFETTO: Can I tell you what I think that one is?

MEMBER HASHMI: Okay.

CO-CHAIR PERFETTO: Because I think it is capturing what you're describing. I think it's that there isn't that full work-up that happens after detection. It just kind of falls through the cracks and it takes a very long time for there actually to be a good work-up and a diagnosis. And I think that was a lot of what were hearing yesterday was that it just took too long for it to happen. Is that what that was intended?

MS. JOHNSON: And I think that came out of our group. So, maybe, David and Ryan and Cyndy want to --

MEMBER REUBEN: There are a lot of

sub-bullets on this, the kinds of things that we thought were absolutely important in this. And these included not only your traditional, you know, CT scans or MRIs or TSHs, et cetera. It really included things like assessment of caregiver support, of burden, advanced directives.

And there were lots of things in this initial evaluation that needed to be done. So, there are a lot of sub-bullets underneath that, things that were much more comprehensive than just ordering a few tests.

MEMBER HASHMI: Just a follow-up question for you.

MEMBER REUBEN: Yes.

MEMBER HASHMI: This, from a clinical perspective, is a very narrow sort of language. You know, I never went to the fact that this might imply, you know, working with the family or access to services down the road or education about services.

I would suggest maybe a different

language that sort of has a broader sense about it than just work-up.

MEMBER REUBEN: Yes. This was really more of an evaluation or an assessment would probably be a better term for it.

CO-CHAIR PERFETTO: Can I ask a question, David?

MEMBER REUBEN: Yes.

CO-CHAIR PERFETTO: Would you say that the second bullet and the third bullet could be combined, if we said, "an intentional comprehensive work-up"?

MEMBER REUBEN: Well, so, the difference between the second and the third bullet, the second bullet has these time frames and documentation parts. So, if you want to lump everything together and one very long bullet, that would be fine. There wouldn't be any problem with that.

But, yes. What I would say is, if there is an evaluation, when you review charts, you have to look for was there a TSH check and you might have to go through, there might be seven or eight bullets that have to be checked to pass that quality indicator. And here's where that specificity can come in and, then, you can add the timeframe and the documentation. You've got a frowny face.

CO-CHAIR PERFETTO: There are other people.

MEMBER REUBEN: Okay. All right.

MEMBER CORDELL: I was just going to say, what's a little surprising is there is no bullet on connection to community-based services. And, with dementia, that's such a critical part of support. And, yet, it didn't bubble to the top.

But I think, unless it's embedded in a lot of these, I just think that's one thing I'd hate to -- I mean we know that a lot of doctors say, you have Alzheimer's disease. See you in six months. And that's about it. And, then, the ones that say, you know, contact Alzheimer's Association or other resources, they do and they find some support.

So, I'm just bringing that out that I want to re-vote and make sure that's on there or make sure, if it's embedded in there. Everybody here we've been talking all yesterday about how important, you know, those types of resources are for this population.

MEMBER COOLEY: Your voice broke up there. So, what was the basic thing? It was care coordination? I couldn't hear what you were saying.

CO-CHAIR PERFETTO: Connection to community-based services is missing from this entire list?

MEMBER COOLEY: Yes. Connection to community-based services. And, also -- this is Susan -- care coordination. I mean I'm not sure if that's in there.

CO-CHAIR PERFETTO: Right.

MS. JOHNSON: So, one quick question. Under both person with dementia and family caregiver, we have that dementia-capable system with community. Would that get to that, or is that something different?

CO-CHAIR PERFETTO: Okay. So, we've got a couple things on the table and I want us to keep track. So, one is the question about whether or not dementia-capable healthcare system includes this linkage to community-based services or not. We have to clarify that.

I don't think we still have completed the discussion that we were having on whether or not the diagnostic evaluation and the core dementia work-up could be combined in some way, if we changed it to "an intentional comprehensive work-up" and we defined what we mean by comprehensive. And it includes the things that David was listing off. So, do we have closure on that one or does anyone want to have more discussion about that one?

MEMBER COOLEY: This is Susan. On the core dementia work-up, this raises another issue that may have been in the heading of a parking lot issue.

I don't know if this was discussed at the time or alluded to, the issue of to what extent are the measures we are trying to develop or advocate for, to what extent should they be ones that can be automated, pulled from the electronic medical record versus ones that require a chart audit, people reviewing.

I raised that issue because, obviously, anything that is automated and from the electronic medical record, of course, they'll only get it from places that have electronic medical records at this point, but that is much simpler and less costly than a chart-audited type of measure.

With the core dementia work-up, we, at VA, have a pilot measure we've been working on that is based on the desire to have a basic dementia work-up, before a person gets the diagnosis label of dementia. And it has core components of a dementia-relevant history, physical exam and laboratory tests and within a certain timeframe before, up to one month after, the dementia diagnosis is given.

But it's pulled through a chart-audit process, which is very labor intensive. Just as the person who was speaking before, I can't remember whose words, I don't know. There's lots of pieces to it. There's lots of pieces to it. And, where it's a past history part, it's like a Chinese menu, this number of this plus, you know, X number of that in order to pass the physical exam part.

There's, you know, all these different pieces and, for the laboratory tests, such and such pieces. So, it's complex. We haven't been able to go very far with it because it takes a lot of attention to try to figure out. We haven't developed it very far.

But, anyway, that's the concept of it but it's labor intensive, because we have an external peer review chart audit process and it's complicated. So, that's one example. One could, you know, without saying everybody must have exactly these pieces in their core dementia work-up, we have an example of something like that. But it is based on a chart audit process, as opposed to an automated.

And that raises the automated versus chart audit issue, in general, about these measures.

CO-CHAIR PERFETTO: So, Susan, thank you for that. I think maybe one of the things that we just put on as a sub-bullet here is that we understand that there would be logistical and technology issues, in order for this to actually become a measure and, especially, like a composite measure of some type that would take all of these things into account.

But that there may be a way to do this incrementally, where we look for a few key things and, then, work to something that's more comprehensive as automated data become available. But that, if we, at the very least, could make a recommendation that there is something that is considered a core dementia work-up.

That is something that sounds like it doesn't exist anywhere that we could refer to today. But there may be a VA prototype that we could turn to. Then there may be some way that we could at least make a recommendation that this be something that gets developed in the future. Does that sound like a way to go?

MEMBER COOLEY: It would be possible.

MEMBER KAHLE-WROBLESKI: The other piece to that, too, if we can just flag, if part of the diagnostic pathway, the core dementia work-up, all of that, to think as well, if we're looking at primary care or specialist care, how that would work exactly.

I don't think we have to answer it right now but, if we can all be thinking about that as well, because that may look different as well.

MEMBER REUBEN: So, a couple of comments. One is I think, when we talk about this diagnostic work-up, it really is beyond just the medical stuff. It really is about, you know, assessing the patient, the environment, the caregiving situation, the resources, all of that stuff.

And we actually went into it in greater detail in our breakout group and I can help with it and we did this in a group's time.

The other thing I want to pick up on is Cyndy's point. Is these are all, you know, kind of no brainers. These are great. Rah, rah. We love them all.

What I'd like to know is kind of what was left off the table, in this prioritization because where I think, you know, these things connected to social service agencies, PPOs, et cetera, all those stuff are still really important. They didn't get enough votes to make it onto this slide but those things are really important. Thomas? Okay.

MEMBER CARNAHAN: Yes. I guess, just in the interests of lumping maybe, the connection to community services could be part of this support of the caregiver. We were kind of looking at that yesterday and thinking that might capture that concept.

Yes. Just to reiterate, I think the diagnostic work-up could involve a whole lot of different things. Are they eliminating medications? You know, you just hear so many stories about people getting misdiagnosed because they're delirious or the diagnosis doesn't happen for so long.

But, also, following to make sure that they're eliminating other potential causes of cognitive impairments.

MEMBER GROSSMAN: So, I agree with

the comments about tests and core dementia work-up broadly to include not just the patient but, also, to include the environment and the setting in which the patient is living.

But what I wanted to comment on in connection with dementia is that it's disappointing that there's not anything that goes before detection should lead to diagnostic evaluation. There's a nice flow through the person with dementia to work somebody through the system.

But, in my clinical practice, the major problem that I encounter is that detection rate is low, takes a long time. I see folks after they've been to three or four other people, not only their GP but, also, other specialists. It just takes time and it would be wonderful if we could bump up that detection rate.

How to do that, again, I guess I return to the aspirational issue of education.

It's very, very difficult. Maybe it's not just at the level of the GP or the internist to worry about things like falls. Maybe that's an indication of somebody who has dementia.

Maybe that also has to be accomplished at the level of the community. So, is this part of dementia-capable community? I don't know. I'm not sure how that's defined. But I really think that we have to work hard at the beginning. This is something that's oftentimes left off the table, as David said, to try to help the entire workflow go better.

How to measure this? You measure it by looking at the number of people that are seen before somebody like me actually sees somebody with dementia. So, I think it's possible to quantify the kind of thing that I'm trying to target.

CO-CHAIR PERFETTO: Katie?

MEMBER MASLOW: To Cyndy's point,

I think that the dementia-capable system is a coordinated healthcare and community care system. And, so, if you move the slash back one word and put "dementia-capable healthcare/community care system", would say I think what we probably meant. And it would be a stronger statement. What do you think, Cyndy?

MEMBER CORDELL: Yes. I think that just somehow we have to capture that.

MEMBER MASLOW: Yes.

MEMBER CORDELL: Because I think it got lost in the way this was written.

CO-CHAIR PERFETTO: And you're pointing out that we emphasized "healthcare system" in that bullet and it should have been "health and community care system"?

MEMBER MASLOW: Right. And, plus, when David's suggesting put it in the assessment --

CO-CHAIR PERFETTO: Yes.

MEMBER MASLOW: -- then we would

have it at least two places.

CO-CHAIR PERFETTO: All right. Very good. Kris?

MEMBER KAHLE-WROBLESKI: I was just going to echo what Murray said, because I think that is a critical piece and Susan alluded to this yesterday, as well, that it's not. And I'm wondering actually if it's how we stated things in our Group 1 that made it hard to capture detection on its own.

Because I think the closest we came was that those at high risk should be screened on a regular basis. And Susan had made the point yesterday that it's not just about a high risk group, that there are lots of people with overt signs and symptoms of dementia that aren't captured in the system.

So, I'm wondering if it's a wording around detection being part of the regular elder care system. I'm not sure how we work on it. But, maybe, this is something, Karen, that, when notes go out from this, there may be a smaller group of us that may want to sit down and think about what the measures would be, what would be feasible.

Because I think that can be overwhelming, but, certainly, in the UK, they're trying to do that. They're trying to look at increasing the prevalent numbers of people in the UK with dementia, because they know that there in the system right now they're not all being captured.

So, there are probably some lessons from other places. Some states have registries that seem to do a nice job of capturing that. So, we can probably look in a few different places and make sure we capture that in a way that can be quantified.

CO-CHAIR PERFETTO: Mark?

MEMBER SNOWDEN: Yes. I was in the group that came up with Number 2 and I don't have any issues with moving the third bullet into it. But would point out that part of what our group did, and this was probably cheating, but it's got a number of measurable outcomes in that string. And I'm not sure I would want to forget about the ones at the end because we are spending so much time about this diagnostic evaluation that's at the beginning.

CO-CHAIR PERFETTO: Yes.

MEMBER SNOWDEN: So, to remember, I think that there are several key points to that. I think the other thing that's sort of missing is we talk a lot about what we want the system to do. But it's not clear to me that we've completed the link to make sure that that information gets to the person.

And, so, to me, just as it is important for the system to know that a diagnosis is documented, I think somehow the person and the family need to know the diagnosis. Because, if the only place it lives is in the chart, it's not really going to help us as much.

I intentionally stayed away from

the core dementia work-up. So, none of those 25 are me and the reason is I would actually argue that that concept is what drives the delay to diagnosis.

The number one thing I see in trainees is that they refuse to say the diagnosis until they get this work-up. And, by the time the work-up is done, all they really then say is that the work-up was negative. But they never go on to say, and this is what you actually have.

And, so, I would actually say, if we're going to think about emphasizing work-up, to remember that it can have the unintended consequences of delaying what we really what to get to. And I don't think of things as reversible. I think of much more as comorbid.

The last point was about the 31 votes. To me, that was a vision and it was easy to vote for the vision because it can include anything I can imagine. And, so, at some point, we would have to make that much more specific.

And I think, then, we would start to see how probably must of us have a different view of that elephant.

CO-CHAIR PERFETTO: Okay. Matthew?

MEMBER JANICKI: I was going to point out a couple of things. I think one is that, when we're thinking of how to organize standards, you want to see how clusters fall and, so, the standards kind of stick together in terms of some kind of a outcome/function.

And I think that calling this the person with dementia is probably a misnomer. What we're talking about here is the determination of dementia. And these factors that we've been debating now all have to do around that particular focal area.

And I think, also, that the determination has to do with, also, excluding, you know, the presentation of symptoms as being dementia related. There may be something else and we see that in the folks who would have intellectual disabilities as well.

I mean with Down Syndrome you have other kinds of conditions like decreased function, thyroid conditions and over medication and other areas. So, you want to make sure that, when you're doing that assessment, you're actually determining the correct thing I think. And, then, if you find it's something else, then you go on a different way.

The other couple of things I wanted to mention --

CO-CHAIR PERFETTO: I just want to, not that anybody has to answer, but just throw a question out. Should we relabel that first part that's something like "Detection and Diagnostic Accuracy" or something like that? Just something to think about, not an answer yet.

MEMBER JANICKI: Yes. I would strongly suggest that, if you want to cluster these, then you have the title that seems to relate to the cluster. I mean the person with dementia flows through the whole system, all of the things you're going to do.

The other thing I wanted to mention is the issue of special populations. I mean one of the considerations in this whole process of determination is the effects of culture and cluster groups and minority populations and people with different conditions, particularly intellectual disability among others.

And I think any kind of diagnostic center needs to have the capacity to recognize that there is an influence from culture and values and other factors that will confound sometimes the diagnostic process. And, specifically, with intellectual disabilities, it's not a one-shot diagnostic process.

You need to do it sequentially,

because you really are measuring the person against themselves over time to see if the decline and other dysfunctions are playing out as part of the process of disease of the brain as opposed to intellectual disability.

So, that needs to be built into the standards, if there's a sensitivity to these other factors. Language problems, for example, is communication with someone who is a non-English speaker, trying to determine if they respond well to your basic diagnostic tests and things.

I think the other thing that I wanted to echo that Cyndy and others have said, you know, one of the things in the determination process you're really seeing most likely with early determinations are early-phase issues, because that's when you start to see the signal symptoms. If you're down the line pretty much, it's usually pretty much determined what you're doing.

So, the community aspects are very

important in that early-determination phase, because there's a lot more supports that are kicking in and all the remedial and adaptation issues that come in to play, when someone is experiencing early decline or early symptoms of dementia.

So, it's much more important I think from a perspective of coalescing supports to consider that whole community phase. So, I agree totally with Cyndy. I know, from our field, that the community aspect is critically important in terms of providing care in the community for folks, as they begin to become diagnosed.

So, those are some suggestions. I think that, again, the notion of clustering I think, if we go back, and even some of these other titles, if we focus the standards on the area that's going to be evaluated, for example if it's the individual in the determination process, that's one.

If it's the nature of how

caregivers are supported, that's another. If it's the nature of how an individual is then supported and what they receive after the determination, that's maybe another. So, there may be other features that we want to cluster some of these discussion points that we've had in those circles and things. So, those are my comments.

CO-CHAIR PERFETTO: Lynn?

MEMBER FRISS-FEINBERG: Just to pick up what Matt was saying, we really didn't talk about health literacy at all yesterday. And that, in cultural competency of the healthcare and social service professionals is critically important.

It's one thing for us to say the importance of educating a family about what to expect. But, if they don't understand the language that we're using to convey that, what's the point? So, I think we need to talk about teach-back and different strategies and really drill down on health literacy in particular.

CO-CHAIR PERFETTO: We're going to move to the next slide. Okay. So, these were things that you gave blue dots to. And, so, they were things that you felt were somewhat neglected in the dot process but that they were really important to the category that they were in.

And notice what the first bullet is, connection to support services in the community. So, it did bubble up. It just ended up on Page 2. Transition of care, other illnesses, person-centeredness, which I think actually does tie to one of the things that we had on the first page.

Need to know who's the proxy decision maker and, then, the other caregiver support, education on what to expect and caregiver burden and strain, which I think does tie to a number of things that are on the first page.

MEMBER JANICKI: I was going to

point out something that you just brought up. I think that, as we look at these, there are going to be a number of cross-cutting issues that will appear under each cluster. I think it's important that these cross-cutting issues need to be embedded in the standards for each area that you're looking at.

CO-CHAIR PERFETTO: Yes.

MEMBER JANICKI: So, it's not untoward to see this coming up.

CO-CHAIR PERFETTO: Yes.

MEMBER JANICKI: And, it's a consideration that we should, you know, give it some thought.

CO-CHAIR PERFETTO: Yes.

CO-CHAIR FELDMAN: You know, looking at the blue dots and then going back to the priorities from Day 1, you know, it strikes me that, because of the concept of a composite measure with bullets under it, somehow the whole notion of the things that have to happen for the family caregiver, in my mind, is more expansive and less medical in the message it conveys than what we say about person with dementia on the first page.

And some of that, then, is reflected in the blue dots because, you know, we don't specifically talk about connection to support services in the community, although we've addressed that. And even our mention of, you know, transitions is really about hospitalization and long-term care facilities.

It's not more generally about transitions into community-based services and so forth on the person centeredness, you know, although actually one could include that under the shared decision making, which we have for both person with dementia and family caregiver.

And it seems to me person centeredness, which is our blue dot on the second page, is quite likely part of the shared decision making, you know, and goal setting which we want for a person with dementia and family caregiver.

But I think that it seems to me that had we chosen a more composite approach toward the person with dementia on the first page, some of these things would have automatically been captured.

CO-CHAIR PERFETTO: They would have made it.

CO-CHAIR FELDMAN: You know, I also think that it's very difficult for a group like this to end up with the final wording of things and, so, if we can, you know, sort of reflect our views and feed them back to the people who are going to do the ultimate wordsmithing and, then, I'm sure we'll have more than one opportunity to look at what emerges.

But right now, the first page for the person with dementia, just in general it just sounds much more medical than I think any of us really intended it to be.

CO-CHAIR PERFETTO: Agreed.

MEMBER TENO: I think it would still be helpful to think about who's the accountable care organization and what measures you would have because it's really different if it's the state or, potentially, a county, as opposed to a home health agency, as opposed to a medical home.

You know, that's how these measures -- and how we get accountability is by understanding who we hold accountable for this episode of care. And it might be helpful to think about each of these constructs and how you would measure them.

So, for example, you know, detection is a huge problem. So, where is the leverage system within it? The leverage system could be within medical homes or within ACOs. You could require ACOs to do a routine mini medical status exam or some other type of shorter form on a yearly basis, on all people above a certain age.

I think you've got to talk

opportunistic and you've got to also think about the practicalities of putting these measurements in place. Otherwise, a lot of this is going to be pie in the sky and not operationalist.

CO-CHAIR FELDMAN: I would like to be guided. I agree with what Joan said and I saw a lot of nods here. Is that appropriate for this exercise? I mean I think we all have in mind that somebody is going to be accountable for these things or more than one entity. But how do we approach that?

MS. JOHNSON: Well, actually, why don't we go to the next slide real quickly. Part of this may be the way I set up the slides. So, what I wanted to do in the first three was show you what came out of yesterday. This one here and, believe it or not I'm actually answering a question. The next one is other concepts with some support.

So, these are things that they got a few. I didn't put the numbers in, but they got a few things but not a lot of blue dots and not the 20 or 30 weighted counts but, again, some of these things that you've mentioned today. So, let's go to the next slide.

So, what I tried to do here was add in a few of the blue dots into the thing. So, I wasn't able to group too much there. Go to the next slide.

This was asking about the caregiver support. So, there were several blue dots and other things that came that were caregiver that didn't quite make it to that composite. So, now, let's go to the next slide. And the next slide.

So, here's where I get to some of the questions. And, Joan, you'll notice your question is going to be on all of these slides. So, I actually started with the family caregiver one, because that one was easier in my mind. That seemed clearer.

So, you had the idea of the

support for the caregiver and all those things underneath and, so, the caregiver capacity and confidence, I guess my question there was is that the kind of thing that you were talking about under assessment, because I wasn't exactly sure? And would that fold in under there.

Under training, caregiver education I guess would come under there. But that's still a question. But the burden and strain seem to be a little bit different. Is it, was another question or is that something else? And, then, finally, who should be held accountable?

So, you know, I guess one question is are you still conceptualizing this as one composite with all these different things and, if so, are the things that I put under, do they belong? Does anything else go in there? And, then, finally, who should be accountable? So, I don't know. Is it easier to think about it like this or --

CO-CHAIR PERFETTO: How does the group feel? I mean you brought up the issue of accountability and we're trying to, as we said yesterday, lump some of these things. And I don't think it's practical to think that we can make a recommendation says there should be a caregiver composite and it should include these 26 things.

I think we should think a little more conceptually about what we're recommending and that issues with the caregiver are very important. Here are the kinds of things that measures could focus on in order to capture quality of care, as it has implications for the caregiver. A composite of some sort, eventually, would be a nice thing to have and it should capture these kinds of things.

But I don't think we can develop a composite and it should have everything, which is, as we said earlier, a little bit not practical. And then we get to Joan's question of who's accountable? Where would we say we would direct this to, if this was going to happen?

MEMBER HASHMI: If I work backwards from the accountable entity, then the way that I'd construct the composite is a composite index for these concerns for the healthcare system in a composite index for social agencies or community agencies. And that way I've got the accountability thought process built in. And, then, we can get down to the specific metrics. You know?

CO-CHAIR PERFETTO: But what I'm hearing you say is that you wouldn't hold a particular caregiver who's taking care of an Alzheimer's patient, in any way accountable for the caregiver component?

MEMBER HASHMI: There may be. So, in the community component, there may be a caregiver-specific metric: competence, knowledge, technical skills, et cetera. But I will leave that up to the folks who sort of build the detail metrics.

But I would divide it by healthcare accountability and, then, the community accountability. And that may be part of, you know, whether it's a family caregiver or a CNA or whoever.

MEMBER REUBEN: Yes, I very much agree with what you're saying. I think we can have some composites. We can have some composites and those composites have kind of general categories of things that need to be done. So, for example, the assessment one, it should have a medical assessment. It should have an assessment of resources available to the caregiver and caregiver needs, you know, these kinds of things.

There's a assessment of who is the spokesperson for the person. There's an assessment of advanced directives. So, there's maybe a half a dozen things under each of those. But those are the kind of key elements you would need to pass a quality indicator, those that have to be documented somewhere.

And a lot of this is kind of categories and bullets here. I'd certainly volunteer to help with this. But it needs some cleaning up. You know, caregiver education is not just what to expect. It's actually skill training. It's how to manage problem behaviors. It's how to empower caregivers to talk with the doctors and get enough out of the system and partnering with your doctors, savvy caregivers, all these kinds of training programs that have been developed for this.

But, you know, it's not committee work. You know, this is somebody sitting down and coming up with a draft and saying, how does this look?

CO-CHAIR PERFETTO: That's exactly where I was going with my comment is that we don't have to dive into that and we shouldn't have the expectation that a perfect composite measure is going to come out of this. The expectation is that our recommendation is that this is the direction measurement development should go in and that, if HHS is thinking about funding something like this, they should get bang for their buck here versus someplace else.

MEMBER REUBEN: Well, I would suggest that a product from this Committee or this group here could take it further than that. You know, to actually draft what those elements are rather than, you know, saying here. Go ahead and deal up a composite. You know, we've spent a lot of time thinking about it. There's a lot of expertise in the room.

CO-CHAIR PERFETTO: I think we should list whatever we think should be in there.

MEMBER REUBEN: Yes. Okay.

CO-CHAIR PERFETTO: I think those characteristics should definitely be there. Yes?

MEMBER BARTON: I still have my question. So, now, I'll ask. So, when you said a minute ago, what about the caregiver, were you implying that there's actually something that the caregiver is required to do?

CO-CHAIR PERFETTO: My question was coming from, if we're only going at it from the community side, would you not hold a physician accountable for never having asked the caregiver whether or not they knew about certain resources or had access to resources or asked if they were, you know, seeing their doctor or having a medical exam or getting counseling or anything, bringing up the caregiver support with that caregiver, when they're actually taking care of the patient and not making that connection.

Would that be? Because what I heard Razia saying was that she was directing her measures more toward the community, as opposed to holding a clinician accountable.

And that was just simply a question.

MEMBER BARTON: Okay. Thanks.

MEMBER CARNAHAN: Just to address that, I think our group was thinking in terms of a clinician educating a caregiver on what resources were available and evaluating these things.

MEMBER MASLOW: I think it's really important to be sure that who's accountable include community agencies. So, it's not like it's all the medical care system. Community agencies can be held accountable. They are held accountable. And, so, that would, again, bring in community agencies early, when we're thinking about who should be.

So, it's not only a physician who can do the things, who can ask caregivers what they've got. Other people can do that, too, and are better than physicians at doing it, by and large, except for David. But I think that it's really important not to center completely on healthcare and, then, say everything is accountable to the healthcare system or provider.

And, if it's an integrated system, it's still accountable to the community-care part of that system, if it belongs there.

MEMBER COOLEY: This is Susan. I might not be quite understanding, Katie. What is the leverage that the government has? Maybe I'm mixing things up, in terms of who's going to be collecting the data and using the data. But, in what way would some entity have authority over community-ordered basis to collect information and hold them accountable for something? I don't know. And maybe I'm going to narrowly on who these measures would apply to.

MEMBER MASLOW: So, I think that you say that because you have an integrated system.

MEMBER COOLEY: Right.

MEMBER MASLOW: But community

agencies receive federal government and state government and community government funding and can be held accountable in the same say as healthcare systems can and are.

MEMBER COOLEY: Right.

MEMBER MASLOW: And, if you have an integrated system, the integrated is I hope asking both. So, just in thinking about the Medicaid or dual-eligible systems, those systems are and should be holding community agencies accountable when there's public money. And there's a lot of public money.

MEMBER COOLEY: Okay. Good. I'm sorry. Thank you for lining up the reality. Thank you.

CO-CHAIR PERFETTO: And I think we're also thinking of what Katie mentioned earlier, which is that there are community organizations out there who have been asking for these kinds of measures. And, so, they would be defining themselves and defining their own numerator and denominator.

MEMBER COOLEY: Good.

MEMBER TENO: I'm actually going to be synchronous here, which is often difficult in these things. So, Katie listed a really good starting place. But there is a whole bunch of agencies who we could hold accountable. Anybody who is in charge of a dual program, as an insurer, should, on a yearly basis, survey the family members about the quality of care, who they have listed as next of kin on those people who have dementia.

You could take a look at MA programs. You could take a look at medical homes. You could take at, if you want to be designated as a dementia clinic or you have official NIH money as a dementia clinic, you have to meet these quality standards, PACE, SHMOs.

So, there's all these entities that you could get a population, easily identify who they are and hold them accountable. What would I do? There would be a chart-based measure that would capture all the things that David was talking about.

My concern is, when you create that chart-based measure, it's going to get a ceiling effect very quickly, because it's sort of like training people to the test. That will happen. But, on the other hand, bringing the bar up to that test might be a really good thing.

And, then, you know, I think what I would do is I'd design a survey that would happen every year and it would touch on a number of the domains that we talked in our group: person centeredness, you know, the treating of dementia, sort of cumulatively being responsible, you know, things like that.

I think that the amount of work that would need to go into creating that survey would be substantial. But, on the other hand, I think it's a leverage system to really start changing some of the quality of care and hold these agencies accountable to the consumers and, you know, also get at my concerns about these dual-eligible programs and whether they're really, truly living up to their ideals and goals.

CO-CHAIR FELDMAN: A couple of points that I think are also synchronous, this discussion reminds me of the discussion that has sometimes occurred about whether, you know, the concern over, you know, shouldn't there be like one point that controls who goes to a nursing home or a community-based agency or whatever.

And I think, and you can correct me, D.E.B., but the view in the more sophisticated states is not that there's a single point of entry but all points of entry or any point of entry with common measures. And that's the aim of where we want to go.

So, I do think this is an example of where we want to be very careful that we don't absolve the healthcare entities because, frankly, the healthcare entities are the place where many, many people, perhaps even the majority go to get their first piece of information about this, outside their own personal network. So, we want to be very careful we don't absolve them.

On the other hand, there clearly are both responsibilities and privileges of community-based agencies. Because, if you make them responsible for something, perhaps that's also some sort of leverage for them. But, they're generally less equal in this.

With regard to Joan's comment about the survey, again, for years, I don't remember how many years ago, I was the Chair of a steering committee for the National Center for Health Statistics about what they should do with their long-term care survey stuff, which tends to be facility based.

And, even then, we had this whole discussion about what you really need is a person-centered survey. Now, that costs a lot of money to my knowledge and we still haven't got that person-centered survey.

But I think this is another area, Joan, where we could weigh in and, even with the comment that there are other benefits about, you know, that read down to other parts of the regulatory and payment system from a person-centered survey. And that, then, feeds into our notion of person-centered outcomes.

CO-CHAIR PERFETTO: Mark?

MEMBER SNOWDEN: I'm just going to respond to the last question about accountability and, to me, it doesn't matter who, as long as someone is and as long as the rule that was established yesterday that the data has to come from the aggregation of individual-level measures, whether it's the person with dementia or the caregiver.

Because, then, I think you leave flexibility. In my system, there's a lot of stuff that gets passed from the system to the provider. But then there's a lot of stuff that the system takes care of that I'm not individually responsible for.

And, so, I think that's the beauty of having systems that let them choose how to, I think, best marshal their resources.

MEMBER REUBEN: I'd like to pick up on Katie and Joanie's train of thought here. In our dealings with this, and, Joan, you're absolutely right. In systems such as SHMOs and such as special needs plans and things like that that are very tightly integrated, this is a lot easier.

But, in the real world, a fee-for-service Medicare, this is incredibility difficult. This is incredibly difficult because you really don't have that kind of accountability, especially with community-based organizations. And, to be honest with you, that has been for us the biggest challenge.

The biggest challenge is how to hold community-based organizations accountable and how to get them to share the same kind of records and the same kind of systems, so that they're not working at opposite purposes, not cross purposes, but in different directions.

And, so, that linkage has a very tenuous linkage at this point. It's very tenuous, so that there are these community-based organizations that are doing their thing. But they're not very well connected to the overall health system.

What's happening, what we're seeing more and more is that the larger health systems, the Kaisers, the large health insurance companies, the CareMores, they're bringing these services in. They're not farming them out. And, you know, if community-based organizations are going to survive, they have to be integrated some way in.

And, then, who is accountable? And, from my perspective, we've made the health system accountable, because that's where the money is. That's really where the money is. And I think, having a parallel system of CBOs having their own kind of plans, their own screen, is just going to be very difficult. You're going to get fragmented care. So, that's my soapbox.

CO-CHAIR PERFETTO: So, David, a question for you, just for you to think about. Could there be some measures that could be used to leverage more collaboration or offering of the kinds of services that you're talking about in a collaborative way because they have to meet a measure? Could that help the situation?

MEMBER REUBEN: Yes. There could be. One of the things you could do is, through documentation and care plans. In fact, that there are care plans that have input from both the health system and community-based organization. Responsibility for completing tasks is clearly assigned and documented, those kinds of things.

But, you know, it's going to

change the way CBOs do business. That's okay.

CO-CHAIR PERFETTO: I think that's going to happen anyway.

MEMBER REUBEN: I hope so.

CO-CHAIR PERFETTO: Katie was next.

MEMBER MASLOW: I think that this is a great conversation and it is the reason that the health system can work the measures is because the health system has the money, in my view. So, it would be a different picture if the Alzheimer's Chapter in L.A. had that amount of money and was asking you and UCLA to respond. So, I think that that's a factor here.

And I think that community organizations are accountable to their own objectives, the objectives that they name and they should be more accountable, perhaps. But some are very accountable.

But one thing I wanted to go back to and this is with respect to Joan's idea.

I think that experience of care measures are really important here and that, as the one exists now in Hospice going out to families, there should be a systematic assessment of families and I believe of people with dementia in early stages.

And the CAHPS measures, that whole batch of measures that we have now are great. So, imbedding a question in a CAHPS measure is hard, because it can't be too long. But it could be extremely valuable. So, there could be a CAHPS measure for, if we could identify people with dementia, for those people and people and their family caregivers. And that would get that experience on a regular basis, as you said.

MEMBER GROSSMAN: Certainly, healthcare systems should be held accountable. There's no doubt about that. But that's for folks that are actually in the healthcare system, have some content, some context for the participation in a healthcare system.

But there are folks that we see in Philadelphia where the caregivers don't know that they're caring for somebody who has dementia. And we're missing those guys and it's from that perspective that we have to hold community resources responsible as well.

There are folks that will come into my clinic and say, gee, I need help with my mom. She's having difficulty with her walking. And the fact is that she's been demented for ten years and there is no recognition at all that that was an issue that's going on.

And, so, we have to have community resources become more responsible, become more aware of what it is that we're trying to do.

MEMBER TENO: So, I'm going to follow up on Murray. I think what you have to do is you have to have a measurement set that makes sense. And, so, to have a measurement set that makes sense, you have to have something about that requires detection. You know?

So, even if everybody can get that with 99 percent of the time, you have to enforce ways that people detect. But, then, I would go beyond to make sure there is an accuracy in assessment and management.

And, then also, a session where they talk to the family and the patient, if the patient's able to participate, if the person's able to participate, about what the meaning of this diagnosis is. And you put that as sort of one set of things.

You have to have a way of getting into the system adequately but, also, once you're in the system, you have to have measurement of the consumer's experience and, hopefully, that will help the system function more about quality of care and less about the healthcare industry.

MEMBER GROSSMAN: So, it's easy to find measures, safety, how many falls somebody's had. Aspirationally, there are a gazillion ways to measure whether people outside of the system should be captured and be brought into a healthcare system that's dementia capable. And these measures are there. It's not tough to find them and I think you'd probably capture lots of these.

But I don't think that we're looking at them in the right way. I think we're looking them as a way of thinking about nonspecific healthcare in the community, when all of these are markers of dementia that are not being treated that way.

CO-CHAIR PERFETTO: Murray, this is one of my personal pet peeves is that we have data that we're not tapping that could tell us a lot sooner that someone's having problems. But we're just not looking at that data. And I completely agree with you that we could set up some systems that would probably, using claims, detect a signal that says this person should be checked.

And it's the kind of thing that

we're talking about: they're falling, emergency room visits, lots of doctor visits, those kind of things. I believe Lynn was next and, then, Katie, back to you.

MEMBER HASHMI: I wanted to ask, if I may, both Murray and David, what are your top three referral sources? How do families come to your clinic? How do they get to you?

MEMBER GROSSMAN: They come to our clinic for lots of different reasons. One reason is folks are very, very frustrated. They've gone around. They've visited four or five, six people. Other physicians have tried things to make their loved one better and failed and they see things continuing to go down the tubes.

CO-CHAIR PERFETTO: Murray, I think Lynn was asking how do people find you?

MEMBER GROSSMAN: I'm sorry?

CO-CHAIR PERFETTO: I think she was asking how they find you.

MEMBER GROSSMAN: How do they find

me?

CO-CHAIR PERFETTO: Yes.

MEMBER GROSSMAN: It's frustration. They've been to four, five, or six people and they finally come to see me and ask, gee, please help us. What's going on? They'll go through a litany of things that have been tried previously.

CO-CHAIR PERFETTO: But how did they know they should call you? Did some other doctor tell them, you should go see Murray, or did --

MEMBER GROSSMAN: Yes. Lots of times people will say, oh, yes, he'll figure it out. I've sent somebody to him before and they, you know --

MEMBER MASLOW: Does the Alzheimer's Association send you people?

MEMBER GROSSMAN: Does the Alzheimer's Association send me people? No, I don't think so.

CO-CHAIR PERFETTO: Use your

microphone please. We can't hear you.

MEMBER GROSSMAN: So, there are some organizations that will send people to me. Oftentimes, it's word of mouth. I don't know.

CO-CHAIR PERFETTO: David?

MEMBER REUBEN: Yes. That's interesting. Most is word of mouth. But we actually proactively go to physicians' practices. And this is in the context of our Dementia Care Program. We actually go there and market. We actually go to physicians' offices saying, do you have patients who have dementia? Please refer them to us. And, if you're not sure whether they have dementia but you're a little concerned about them, we have a memory evaluation program.

But that said, I'm not sure I've ever gotten a referral from the Alzheimer's Association or, occasionally, rarely, from the community-based organization. But they don't refer to specific providers. You know, they say, talk to your doctor about this.

MEMBER GROSSMAN: It's remarkably serendipitous. It's all happenstance. So, somebody will pop into my clinic because they dropped their visit. And, so, they put somebody new into my clinic and, you know, lovely son and daughter caring or their mom and they're at wit's end because they don't know what to do. The mom has bedsores, because she's immobile and incontinent of urine and they need help.

They're not thinking about it as something that this is a dementia kind of problem. They're just coming in because they're just overwhelmed.

MEMBER ZWEIG: I would just say maybe a state or an Alzheimer's Association specific issue, too, because, in New York, I would say we often get referrals from the Alzheimer's Association and/or the Lewy Body Dementia Association. So, it just might be sort of the chapter and who's making the referrals as well.

MEMBER MASLOW: I think that word of mouth sometimes is people who are in the community. It always is people in the community and it's someone that knows you that I know that the Alzheimer's Association refers to you but they aren't going to come and say, "The Alzheimer's Association told me to come to see you."

So, when people call or contact a community agency, they receive word of mouth, by definition, right? And, then, they get to you. There's got to be a way. It's great to do the physician referral. I think that's totally great.

But I think that the detection and getting people to someone who actually can respond, that whole process needs to be considered as coming from the community by and large or half or something. It needs to be considered as coming from the community. What we were talking about yesterday in terms of education, public education about what signs and symptoms there are, I think that's a way to get people for an evaluation or an initial recognition.

So, I think the community should be held responsible for getting people to you, in addition to the efforts you're making to actually inform physicians.

CO-CHAIR PERFETTO: Cyndy?

MEMBER GROSSMAN: And, you know, the payoff is that people come to see David or they come to see Eric or they come to see me because we're able to do something to actually help them out once they're there. So, I suspect that there is this kind of feedback mechanism and that should be part of the educational process as well, I think. It's not worthwhile just sitting around at home and getting a bed sore, but there is something that you can do to help minimize that and that's part of this dementia practice.

CO-CHAIR PERFETTO: Cyndy?

MEMBER CORDELL: This is Cyndy from the Alzheimer's Association. So, I do want to say that I know for a fact that several chapters are more sophisticated than others and they have a very great resource of local physicians and centers that they commonly refer to.

It's one of the most common questions that come to our call center. Where can I go with people that know what they're doing? I will say we also are addressing, as you said, the community organizations have to change.

Just a history, you know, four years ago there was nobody in the national office that was looking at bedside clinicians. And, now, that's me. I've been there for four years and that's my background.

And we are struggling right now with how to add physician-type groups or clinics with some type of criteria. We just relaunched our Community Resource Finder, which is much more user friendly. And there is a section on doctors coming.

And it's been an interesting endeavor. We've tried to look at criteria such as, we have these new centers popping up of neuroscience centers of excellence. And we've reached out. You know, why are you saying you're a center of excellence? And a lot of these go, well, we really don't know. I mean it's kind of like a marketing. They just slap "Center of Excellence" on it. They didn't really have criteria.

It's been fascinating endeavor. So, we are really looking at this now trying to set up some criteria. I've been really listening. I like this idea of maybe part of the checklist is, can you handle diverse populations? You know, what can we say here? You know, we can assess, these centers have this.

New York has actually done that. On their website, they've got specific criteria. Now, granted, they're in a very robust area with really great diagnostic clinics. So, they've set their own criteria for their area on their website. And people will call them.

You know, Dr. Smith, I want to be on your website. And we will say, no. We have criteria of who's on, who's not. And we are working on that. I mean it's actually, you know, a goal of mine in the next two years to really have something.

And we'll always have to have disclaimers because we have had issues where we've referred people and they're not taking any Medicare patients. This is kind of starting to happen more and more.

So, some physicians are now closing their practices to Medicare patients. And that has been an issue. So, you know, we don't want to refer somebody and they call and, then, well, we're not going to take you.

So, then you start getting into,

do you take Medicare? So, we do hope to address that and we do know that is a huge gap, because people do want to know where to do that they can be handled appropriately.

And, so, we're going to work on that with some criteria and, hopefully, have that, you know, as part of a community-based resource. But it's not as easy as it sounds, when we really started looking into this.

CO-CHAIR PERFETTO: Yes.

MEMBER CORDELL: But we are trying to address it and I'm actually just gathering some advice and looking at that in a way, you know, kind of have this inclusion/exclusion criteria.

CO-CHAIR PERFETTO: Okay.

MEMBER CORDELL: So, we hope to help with that.

CO-CHAIR PERFETTO: Thank you. We're going to wrap up this section. We've been talking about this family caregiver. I'm going to give Eric the last comment on this one because then we have another slide that we need to cover with these clarifying questions on the individual. So, Eric?

MEMBER TANGALOS: Yes. So, despite the fact that I have a fried computer, I got a three-page letter, email from a daughter yesterday, and it's on my phone, about her mother and a dysfunctional family and somebody taking the reins and doing something about mom's Alzheimer's disease.

And a second message came through my nurses regarding another patient with REM behavioral disorders and the wife can't handle that any more either. The point being that there are very few physicians or providers that will actually take the time to do what needs to be done.

And we've talked a lot about shared decision making. But there comes a point in time when these families are so frustrated and so tired that they say let's pick a direction and go. Let's problem solve and do it.

And, even among the 44 colleagues that I once chaired, there's only a handful in that 44 that will actually settle down and deal with the patient to the extent and length that needs to be taken.

They will blow them off. We've talked about this yesterday as well. We've talked about that learned helplessness that's there. Oh, I don't know. Go talk to somebody else. I'm not a specialist in this.

And, when I look at our charge, our charge is performance gaps. Okay? I think it's a gigantic gap. I think this is where families call out, cry out and want assistance and we have an unresponsive and an unprepared and an unwilling medical system to get the job done.

CO-CHAIR PERFETTO: Thank you. Okay. So, here's the updated list on the clarifying questions with the blue dot put in. And Karen has added some questions to this also. For dementia-capable, who should be held accountable? What type of measures would be quantify this? Who should be the source of data?

And for shared decision making, who should be held accountable? What other types of measures besides patient-reported outcomes measures would be appropriate?

I think we've covered some of this but let's be sure that we've got this page covered and these issues covered well. Kris?

MEMBER KAHLE-WROBLESKI: Just a comment, are we assuming PROs includes care-giver-reported outcomes? This had come up yesterday I think around the proxy report.

But I think, for this population in particular, we just need to be very clear on when we're talking about actual patient-reported outcomes versus what becomes more of a proxy-reported outcome.

CO-CHAIR PERFETTO: And I don't remember who it was that said it yesterday.

But someone yesterday, at least I assumed we were working from the premise that there would be both because early on a patient would be able to report pretty well and the caregiver could be reporting.

But, when that patient can no longer report, that proxy steps in there and having that continuity is a good thing. So, I think we were talking about both, even though we don't say it here.

MEMBER KAHLE-WROBLESKI: Yes. So, then, I think it's just a reporting issue that we need to be very clear --

CO-CHAIR PERFETTO: Yes.

MEMBER KAHLE-WROBLESKI: -- as to when and why we would use one versus the other or both.

CO-CHAIR PERFETTO: Yes. Right. Okay. Does anyone have any other comment about accountability on this one? We talked about dementia-capable community and a little bit about the accountability there. We talked a little bit about the physician's office. Any place that we're missing, any gaps here? Katie?

MEMBER MASLOW: I'm not sure where we are in terms of patient or person-reported outcomes. But let me just say a couple of things about this. I think hardly anyone is knowingly collecting outcomes from the person. Of course, they are because they don't know the person has dementia. But, intentionally, I think hardly anyone is.

And there are some really good what I think are outcome measures for people with dementia and there is some research that David Bass and his group have been doing, so that the measures are validated measures. And they ask the person, do you understand? Have you gotten enough information about your condition? Does your physician listen to you?

How are you doing with your caregiver, not just how you, caregiver, are doing with the person but how's the person doing with their caregiver? So, these questions are really exciting I think and that they're validated and that they've been used.

So, the first study that used them was published in 2004. But it started in '98. And these are good measures. And, if we can't add them to our list, at least maybe our report could call attention to these measures. And I would be glad to send anyone the list of measures, how they're calculated, the data that came out.

But VA just paid for this intervention, Partners in Dementia Care and the paper is out now which measures these outcomes in I think, depending on time, 300 down to 100 people, veterans with dementia. They can answer and their answers are correlated with what they got or what they didn't get. So, it's really an exciting area and it is person-centered. It's by definition person-centered..

CO-CHAIR PERFETTO: And, Katie, as

part of Karen's presentation yesterday, she talked about the panel that met two years ago.

MEMBER MASLOW: Yes.

CO-CHAIR PERFETTO: There was an NQF-sponsored panel on patient-reported outcome measures as performance measures. And there is an existing document now that has a pathway in it for, if you have an existing patient-reported outcomes measure, what's the pathway you should go through to turn that into a patient-reported outcomes performance measure?

So, one of the things that we can put in our report is that people who are thinking about patient-reported performance measures could being that pathway with some these existing measures, use the existing NQF pathway to get them to be a performance measure.

MEMBER MASLOW: I think that that would be great. So, I'm just lobbying. Let's do that.

CO-CHAIR PERFETTO: Okay. Done.

CO-CHAIR FELDMAN: Does that pathway include support from the NQF? Because a researcher with a research program isn't necessarily going to be able to mobilize the resources necessary to test something in an organizational setting as a performance measure. So --

CO-CHAIR PERFETTO: But I think that that's part of our duty in our report is to say to HHS, the pathway exists. Some of these measures exist. It could be low-hanging fruit for you to have someone connect the dots rather than start with a blank piece of paper.

MEMBER COOLEY: I think that's a very important point.

CO-CHAIR PERFETTO: Kris?

MEMBER COOLEY: This is Susan. I'm not sure. Was somebody else trying to speak?

CO-CHAIR PERFETTO: Go ahead, Susan.

MEMBER MASLOW: Yes, let her go.

MEMBER COOLEY: Just in relation to that. I'm glad, Katie, you mentioned what you did in kind of refocusing on patient-reported outcomes, kind of back to the visual outcomes plan that we talked about yesterday.

The Indian Health Service has a plan to, in its action, one of its action items in the 2014 national plan, has four person-centered goals. And, so, when I look back at them and the Indian Health Service, their action item is to improve coordination around four person-centered goals.

And here's what they say. "I was diagnosed in a timely way. I know what I can do to help myself and who else can help me. Those helping to look after me feel well supported. My wishes for care are supported." So, I don't know how Indian Health Service currently plans to measure that, to monitor it, but that wording of those items is why some of the things ended up as they did in our measurement grid.

And I can't remember whether they took those four goals from UK work or whatever. But that's getting back to the person-centered thing. And, Katie, as you said, David Bass, Mark Kunik and colleagues' work has some measures but it kind of covers the waterfront of person-centered goals in this area.

CO-CHAIR PERFETTO: Kris? Thank you, Susan.

MEMBER KAHLE-WROBLESKI: So, this relates some to PROs but other kinds of home-based measures. Eleanor, you mentioned it. Susan mentioned it. Let's not lose, as we discuss this, how technology could enable a lot of these things. And where there are some gaps, it could be more around the data structure or the technology structure.

But, if we can make recommendations as well, and to think broadly too, because I am sure there are plenty of eager vendors who would love to help out with PRO work and have innovative aps that could be useful.

CO-CHAIR PERFETTO: Yes.

MEMBER KAHLE-WROBLESKI: So, thinking beyond the standard paper and pencil or even the standard of what goes into an EMR and how some of the technology platforms might be able to facilitate what happens even in the clinician office to make sure that some of these things are easier to use and are a little more friendly to caregivers, who by the way are some of the highest internet users. So, I think there's a lot that we could do with that as well that would facilitate.

CO-CHAIR PERFETTO: Okay. Mark, last comment on this.

MEMBER SNOWDEN: Yes. What I was struck by, Katie, is that the current CGCAHPS has questions that are almost identical to what you said. And, so, I would want us to be mindful that, to the extent that we can merge things, it will be much better than separate, because there really is a thing about survey fatigue.

And, in our system, you can't get a CGCAHPS if you just came out of the hospital, because we know you're going to get the HCAHPS. And, so, at some point, we need to recognize that it isn't going to go away because we put another one, the dementia patient or person will still get this other thing to respond to.

CO-CHAIR PERFETTO: Okay. Well, thank you very much. That was a great discussion and I think we gave the staff from NQF a lot to work with. And we're going to have an opportunity for a public comment and, then, we're going to have a break. But I am not coming back after the break. Kris and I are running for a taxi because we're headed for another meeting in Montreal.

And, so, I am going to be departing. So, I wanted to give my little thing that you're going to ask for later, I wanted to give it now.

And I think one of the things that we need to do is we really do need to think about low-hanging fruit. And, because we've had some really ambitious things here that are great for the future, but we need to think about what we can do now.

And, so, I think some of these things that we talked about, there are opportunities to capture some of these now. And one of the things was what Kris had raised a little earlier. We have databases that we should be tapping that we're not adequately tapping.

And we have to think about new ways to use technology, especially when we think about, with HHS, some of the regular surveys that HHS does. And I know that they're talking about this and thinking about this on a regular basis.

But, in moving into new technology

for the collection of those surveys, how can we capitalize on that to collect some of the data that we don't have now? And I think that's some of the low-hanging fruit that we should be looking toward.

So, thank you all very much. I really appreciated working with all of you and that you all were so active and engaged. And, when we were discussing yesterday the dot dilemma, it was great to have that kind of conversation, because it showed everybody really cared about what we were doing and that you weren't just sitting here saying, whatever you want us to do. We'll put a dot on anything.

So, it was really appreciated. Thank you. And, now, public comment.

(Applause)

OPERATOR: If you would like to make a comment, please press * and then the Number 1.

MS. FELDMAN: We'd also like to

invite people from the public to make comments that they wish, public attendants.

OPERATOR: There are no public comments from the phone lines at this time.

MS. TILLY: I'm Jane Tilly. And I just wanted to follow-up on the dementia capability discussion you've been having with a little bit of information about what we're doing at the Administration for Community Living.

I think maybe the issue brief that people talked about was distributed yesterday or at least I can make it available if it hasn't. It was. So, that's one piece of information that we have given to the Aging Network.

We also have a toolkit that has examples of how states have implemented some of the key elements of dementia capability. And we've had two sets of grants related to this in 2011 and 2013. So, there are about nine states out there that are implementing dementia-capable.

We focus on home and community-based services in this regard. So, a lot of the health discussions you've had we have some information that might be useful. But, primarily, the focus is on the community organizations you've been talking about.

We also have some products from some learning collaboratives that the states have participated in. And they chose the issues they wanted to focus on. And the first set of states focused on identifying people with dementia. That's something that's come up and assessment. So, they have some ideas around that, around training for staff, which was also a large focus for them, and quality assurance.

And, in the quality assurance, what the states wanted to do was, rather than create a new set of separate measures for people with dementia, rather, identify the people with dementia and use their existing systems. And, really, the biggest lift for these folks at the state level was actually identifying those with dementia.

The second set of grants, as I said, were awarded in 2013. And I can't remember. There's another set of three learning collaboratives that are just getting under way. And I know that one of them was around racial and ethnic minority considerations, because of the recognition that those folks, there's just different cultural considerations around these topics.

A lot of this information is available on the website. It's a little bit difficult to find because we're migrating from an AOA website, Administration on Aging, to the Administration for Community Living. So, I can help people find these things if you need to do that.

And I believe that was all I had to say, just to let you know what we're doing.

CO-CHAIR PERFETTO: Does anyone

have any questions for Jane? Can we get the link to those, maybe, included in the meeting minutes? That would be very helpful.

MS. TILLY: Yes. So, what I'm hearing is you want the links.

CO-CHAIR PERFETTO: Yes.

MS. TILLY: And we'll get those to you.

CO-CHAIR PERFETTO: Yes, please.

MS. TILLY: Yes.

MS. LING: Hi. Good morning. I'm Shari Lang from Center for Medicare and Medicaid Services. And thank you all for this tremendous work and for your leadership in this work. I just regret I was not here yesterday to see you marching around with blue dots. That would have been really quite invigorating to see.

I do want to just let you know that this all and the conversation, actually, really aligns well with some of what CMMS has been working on in the quality improvement space to improve outcomes for persons with dementia and, also, their caregivers.

And the concept of low-hanging fruit was mentioned. And, just to keep in mind that measurement and what quality measures may be forthcoming from this effort, low-hanging fruit from our perspective is to be able to use those measures for both quality improvement but, also, for quality reporting.

And I often hear conversations that we think of this linearly and, appropriately so, from detection to diagnosis to management. But also keeping in mind that quality reporting spans physician space but, also, system space for facilities and anywhere a person with dementia would interact with the system, there's opportunity there for us to measure what matters most.

And, along that front, CMMS did host a first listening session for the community and for persons with dementia to find out what exactly matters most. So, if we're going to measure something, what really should we measure, because it matters?

And really it's very well aligned with the conversation here, information that would be useful, that would inform them of what the diagnosis means and what to do about it.

Because, on the back end, when it comes to being able to measure events, unnecessary emergency department visits or hospitalizations or readmissions, if we can apply a consistent set of codes, that could be administratively measured.

So, you know, that can come at this from a different angle. So, anyway, thank you for all of your work.

CO-CHAIR PERFETTO: Thank you, Shari. Does anyone have any questions for Shari?

MS. FELDMAN: We'll now break and we'll reconvene at 10:15.

(Whereupon, the foregoing matter

went off the record at 9:52 a.m. and went back on the record at 10:15 a.m.)

MS. JOHNSON: Okay. Let's go ahead and reconvene, please.

CO-CHAIR FELDMAN: We are now on the slide, I think, not numbered that's up there. It says, Clarifying Questions, Person With Dementia. And down at the bottom it says, for core work-up, what are the elements, et cetera.

But before we do that in the spirit of picking up on a comment that Mark made and in the spirit of Eleanor's departing comment about low-hanging fruit and existing mechanisms, I just thought it would be really useful if D.E.B. could say a couple of words about the --- I don't have the right terminology --- the clinician CAHPS.

MS. POTTER: Mark referred to this as the C and G, which is its internal abbreviation. It's physician and group survey. It's a CAHPS survey for physicians and group practices. And some of the items that Katie was mentioning are included in that survey.

That survey also has supplemental components. There's a medical home component. There's a shared decision-making component. There's care coordination. Some of these are the same questions that they could be incorporated into the CAHPS survey. So, that already exists and is out there in the world and is used for reporting.

CO-CHAIR FELDMAN: In our report when we talk about taking advantage, and I think it's not only of existing measures, really, but of existing mechanisms with, you know, such as this, maybe it would be useful to specifically mention some of the --- just as examples of --- because CAHPS, for example, in its different formations has come up in several different context.

So, now we're going ---- before we go to our so-called parking lot issues, some of which are really important and we've discussed already this morning, we have a little bit of unfinished business in terms of some additional clarifying questions.

So, if you go to the slide that I just mentioned that starts with "For core work-up, what are the elements," I think we decided that we had general consensus that this would include both a variety of medical components, but also a variety of social components. And that we would ask a subgroup to work with the staff to be more specific, not down to the level of it should be this specific diagnostic test or scan, but what are the elements that we would hope would be included in a core work-up.

And Kathy noted that there are already, you know, other measures --- well, Susan, you mentioned the measures, if you will, that are --- or the definition at least used by the VA for a core work-up.

And then it was pointed out that

some of the measures that have already been identified in our environmental scan, like measures from ACOVE and so forth, might well be relevant to this point at the point at which we get down to the measure level.

So, I guess I just wanted to ask, are there any outstanding issues on this particular topic?

And with regard to who should be held accountable, this is ---

MEMBER GROSSMAN: So, at multiple levels, certainly it's the case that the health system has to be held accountable for some elements. Other elements, it should be the community.

CO-CHAIR FELDMAN: The individual, I mean, is this something that's part conceivably of the, well ---

MEMBER GROSSMAN: Sure.

CO-CHAIR FELDMAN: -- ultimately if you got to the person level, it could be incorporated in the CAHPS, the clinical level

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MEMBER GROSSMAN: Right.

CO-CHAIR FELDMAN: -- CAHPS.

MEMBER GROSSMAN: I was just trying to avoid the individual level, as instructed.

MEMBER REUBEN: Well, this really raises the question of kind of who's paying for all this, in a sense. And if the care of dementia is considered to be a medical illness with medical care and that the funds are going to flow through Medicare or other insurances to provide this care, then the healthcare system should be responsible, you know, because that's where all the money is going.

It's very difficult to have dual responsibility here. And it's going to be even more difficult to have something like a state be responsible, you know. They're just not -- they're not geared up for that kind of ownership.

So, in some respects, you know, as Joan was saying earlier if you have an

Accountable Care Organization, if you have a Managed Care Organization, if you have a SHMO, those kinds of things, you know, money flows through the health system and then goes out and then you can hold one entity responsible and that may have to be the model.

Although it may not be the best model of responsibility, it may have to be if that's where the money flows.

CO-CHAIR FELDMAN: And that might be something that we want to comment on, you know, in our other comments in the sense that, you know, many people --- many Medicare beneficiaries still get their care through the fee-for-service system and not through, necessarily, an organized entity.

Joan.

MEMBER TENO: Maybe we should do a few seconds of brainstorming to think about in the fee-for-service system where the opportunity is.

And so, one of the low-lying fruit

is what is the expectations of home health? What is the expectations of a nursing home, you know?

I think the, you know, if you start doing the numbers, okay, and you take someone with an ICD-9 diagnosis of dementia, they're going to go through home health, they're going to go through SNF care.

So, maybe, you know, that could be one of entities to think about who's responsible for.

I think the one sort of difficult thing you have to think about is the denominator, you know. How many of these patients do they get?

But if I were to sort of do this on a practicality basis, I would take utilization data based on someone with an ICD-9 diagnosis of dementia and look at in fee-for-services, where's the money. Where are you going to get the biggest bang of those people covered and take a look at the entities and say, where can you put in quality measures that would leverage improved quality care by having point of contact.

CO-CHAIR FELDMAN: So, I mean, if I could just comment, in the nursing home at least in theory, you know, and in frequent practice, there's a physician on site. I mean, we were talking, you know, here about the core work-up.

In a home health organization, there's not a physician. The whole thing is about getting the signed physician care plan and there's not very much leverage over the physician.

MEMBER TENO: They have an important role in education of that caregiver and part of the initiation in their care plan involves an assessment.

So, I think you have to, you know, the problem with fee-for-service is, the reason why it's hopefully going to be gone in the next decade or so, is that it's all fragmented.

But if we want to do something that will impact while we're doing this transition, we have to be able to sort of follow the numbers and then think about what is realistic to have expectations of those healthcare individuals.

So, for me, I would expect a home health -- they would do the safety assessment, they would assess the caregiver, they would educate that caregiver about, you know, dementia, you know. So, I think there is a couple key tasks that that home health agency should do. Similar things for nursing homes. There are some key tasks, you know.

I think what I struggle with is what's the realistic expectations of the hospital, you know. Because of just how compressed hospital stays are now, what can we expect them to do?

But I would put some expectations on them, you know, that maybe one of the things you should say is that if you met someone with a change in mental status, you need to make sure --- or with a diagnosis of dementia, that you make sure there was an adequacy of the work-up.

Now, can we expect caregiver education in a four-day hospital stay for pneumonia? We can at least expect some referrals.

MEMBER REUBEN: Med reconciliation.

MEMBER TENO: Med reconciliation.

MEMBER REUBEN: This is this fragmentation. I mean, you know, in this fee-for-service environment, you have who's responsible for what and what happens is patients fall through the cracks, you know.

It's just not everybody has home health. Not everybody goes to a nursing home. Hospital stays are too short and so nobody takes ownership. So, there's got to be some ownership out there.

I mean, there are some quality

indicators you could put into the nursing -- so, does a hospital, for example, have a help program to prevent delirium in patients who are demented? That would be a great process, I mean, structural quality indicator.

Was there a medication reconciliation done at the time of discharge? Were patients called afterward?

So, there are things that you can do, but that's just chasing windmills because the problem is not that. The problem is that there is no cohesive plan for this patient. There's no cohesive quality if everything is siloed.

CO-CHAIR FELDMAN: So, we probably all agree with you, but I would like to discuss -- to put some of these structural measures aside for a minute, because that's not really the core work-up, and come back to that because we have that in our parking lot.

And I also want to come back to the detection issue, because it may be much more reasonable to expect some very basic detection and referral on the parts -- of lots of different parts of the fragmented system than it is realistic or even advisable, necessarily, to conduct the core work-up that we would like to be conducted by the appropriate clinician.

So, with your permission, I'd like to sort of come back to that at a different level.

But I think what we clearly have flagged is that accountability in those parts of the system that are fee-for-service is extremely problematic given both the fragmentation of the system and the way in which, you know, the failure of fee-for-service to recognize the extra costs involved.

But I would also turn around and say that many plans rightly or wrongly would come back and say, well, our, you know, you're constantly cutting down on our per member, per month payments. And, therefore, you're going to have to, you know, take into account the extra costs of taking care of somebody with Alzheimer's or X, Y, and Z in order to acknowledge that.

So, I don't think the payment issue actually disappears in almost any part of the system, but it's easier to address in the --- and Razia who is now in a managed care setting is nodding her head over there. So, payment will rear its issue almost no matter what we do.

Mark.

MEMBER SNOWDEN: I would agree the fragmented system is a problem, but it is still here. And so to me, to the extent that there are places that do some of these things, they should be accountable.

The example I would give is I work a lot with the Area Agency on Aging in the King County, Seattle area and they -- they'll have to respond to the U.S. Preventative Services Task Force. And so, they do universal screening and I train them in how to do cognitive assessment.

What is just fascinating to me is that they are told that they are not allowed to tell the recipient or their family members the results of the screen. And I --- because I was trying to --- well, why am I teaching you to do this? Well, they do it because they're mandated.

And so, I would say there are a lot of leverage points on what these organizations will do when they are told you won't get this block grant money if you don't do this.

They do depression screening, they do caregiver burden screening, they do cognitive screening. So, there's a lot of stuff that they do that is related to what we are talking about.

And so, I think they should be part of this accountability as well because they are getting money for it.

CO-CHAIR FELDMAN: And that is the screening and it might also be low-hanging fruit to better understand what the obstacles are, HIPAA or whatever, to actually telling people.

Joan. you want --

MEMBER TENO: Yes. So, I sometimes can be accused of being a labrador looking at food, but I'm going to mention again, the low-hanging fruit is HCAHPS now needs to interview the family members of people with dementia about that discharge planning process.

And, you know, I think that will help hospitals be held somewhat accountable for it.

CO-CHAIR FELDMAN: I think that's come up again and again in our conversation and that's going to be well-noted.

So, let's just go to the next question on this slide, which is, for hospitalizations and transitions, are there components that we're talking about beyond the patient experience?

Katie.

MEMBER MASLOW: Sure. You said at a certain point David had pointed out that part of the care, the core dementia work-up is not paid for by Medicare.

I think that that and keeping a list of what those parts are and using that as an example in the report of what's left out so, you said maybe we should mention that. I think definitely mention it, what you said.

So, on the hospitalizations, I don't know if everyone knows this, but one --- there's the Healthy People 2020 measure on hospitalization, preventable hospitalization. There's data now. The baseline data has been published on this and it is in Health Affairs. In the April Health Affairs, there is an article about it.

And there's a great ASPE report that gives the background on that which also shows ED visits, potentially preventable ED visits.

So, I think this is measurable beyond patient experience. We are going to measure it because it's in Healthy People now and this, I think it's an ASPE report, is showing how they measure it.

So, one might not necessarily agree with what they call a preventable measure in a person with dementia, I don't think we really know that exactly, but it's a great start.

So, I think it is beyond patient experience. But as Joan said, the experience of the discharge, the experience for the caregiver and perhaps also the person, I think, is a good place to be measuring.

CO-CHAIR FELDMAN: Eric.

MEMBER TANGALOS: Yes, I'll try to combine the two. Joan mentioned the 66 percent and then we kind of let that pass real fast, but that's the percentage of patients in skilled facilities that have Alzheimer's

Disease or dementia, mostly Alzheimer's Disease.

And yet when you go look at the number of Alzheimer's patients recorded through the record system, it's down around 20, 25 percent. So, there's a missing of at least 50 percent.

And with hospitalizations, the same way you can argue that even though delirium and dementia are not one and one correlates, delirium is a great stress test for the brain and gives you an idea of what's going on there.

Thinking about composing measures and looking for what we really want to look for, it's really have you made the diagnosis so that you can actually get back to that core work-up?

We have enough population-based studies now that we know what the percentage of patients in a given population should be that have dementia.

Why not reward systems for saying, yes, we have this number of patients that we have diagnosed in the system?

Once you've got the diagnosis, then you're confronted with doing something about it or having done something about it. But, again, I've talked the last two days about people running away from the diagnosis, not engaging.

You could clearly create a population measure that says in this population we know there are this many people with Alzheimer's Disease. Why in your record systems, are we only identifying a third of what there should be?

CO-CHAIR FELDMAN: Can I just raise a question about -- we have this question for hospitalizations, transitions. Is the group talking about all --- I think maybe we need to separate out both hospitalizations from transitions.

First of all, I'm talking about

rates of hospitalization, which, Katie, you started with. Are we talking about all-cause hospitalization here?

Okay. Katie is nodding her head yes. Okay.

MEMBER MASLOW: Just for the reason that Eric said. They're not identified.

So, if you --- there are maybe 10 studies now that look at if you do something as people go into the hospital to look for delirium and dementia, what percent do you get? And then, how many people have anything in their hospital record that says so and the answer is worse than it is in the community. So, 20 percent maybe have something in their record.

So, if you don't look at all-cause hospitalizations, you miss 80 percent of the people by definition.

MEMBER REUBEN: Yes, and another reason, and this gets back to that transitions that came out of our working group, I think, is the whole idea if you have somebody who has dementia, they come into the hospital, worse things happen to them in the hospital. They get delirious, their medicines get stopped, you know, they get bad transitions of care to nursing homes or home health agencies. And unfortunately the patient isn't empowered enough to intervene or cognitively intact. Basically when they go to the nursing home, they can do something about it, yell and scream. Patients who are demented, frequently they'll yell and scream, but can't get anything done about it.

CO-CHAIR FELDMAN: So, that gets us to transitions. But before we do, we've had so much discussion of CAHPS.

Are people with observed cognitive impairment excluded from the hospitalization CAHPS?

Okay. So, this is another example of ---

MEMBER TENO: So, to go one step

forward, anybody going to a nursing home is excluded from CAHPS.

So, just think about that population you're excluding. You're excluding the most vulnerable, the people with most needs, most difficult to care for.

CO-CHAIR FELDMAN: So, if we're talking about examples in our report, we're talking about examples of payment issues. Here, we're talking about examples of existing surveys, instruments, measures for which there are, we believe, inappropriate exclusions of the population with dementia.

And I think earlier we said and what's more, there should be, you know, there should be provision for a proxy to answer questions when appropriate.

And, by the way, I think a lot of people do have a proxy answer anyway.

MEMBER MASLOW: What you just said is what I was going to say. So, if you have 70 or 80 percent of the people are not identified and then you have the CAHPS survey come, it can exclude the identified people, but not the other people.

Then the survey comes and I don't believe that we really know who completes that survey.

So, the survey on those people who have dementia and were hospitalized could be completed by anyone that happens to receive it, or by a person with dementia who might or might not be capable of responding. So, that's a not great situation.

CO-CHAIR FELDMAN: That's true. And at least I know for the Home Health CAHPS, unless you indicate that you are prepared to be identified, you are responding anonymously.

So, it seems to me there are probably some logistic issues that have to be overcome here if we're going to actually use the CAHPS as a vehicle for looking at the experience of people with dementia because the responses are not identified. But --- so, I think there are issues that clearly would have to be dealt with.

So, with hospitalizations we have identified both objective measures, the rates of hospitalization, and we've identified subjective patient -- person-reported measures.

And for transitions, we have talked about there are person-reported measures out there that have actually been endorsed by the NQF.

Are there objective elements of the transition process that we would like to identify here like medication reconciliation or? David?

MEMBER REUBEN: Can I go back? You just said the rates of hospital admission would be a quality indicator. Could be a --- I think that's really dangerous.

CO-CHAIR FELDMAN: Well, I think we were talking about --- Katie, what were you talking about? Is it at a community ---

member MASLOW: It is --- we have

two Healthy People 2020 measures and that is one, preventable hospitalizations in people with dementia. So, it is being measured.

MEMBER REUBEN: So, that's actually a little different thing. Preventable hospitalizations is a different story than hospitalizations.

CO-CHAIR FELDMAN: Yes.

MEMBER REUBEN: I mean, one of the things you could get, this is interpreted that you don't hospitalize patients with dementia.

You just be careful what kind of -- how this is said, because it could be interpreted very much the wrong way, you know. They deserve care, too.

CO-CHAIR FELDMAN: Absolutely.

MEMBER REUBEN: I know you guys agree.

CO-CHAIR FELDMAN: Okay, but this is a community level --- well, not necessarily a community level. It can go ---

MEMBER REUBEN: So, the preventable

one, yes, that's fine.

CO-CHAIR FELDMAN: Right.

MEMBER REUBEN: Saying, you know, just reduce the rates of hospitalization, I think, you know, you might be getting ---

CO-CHAIR FELDMAN: Point well-taken.

MEMBER REUBEN: Thanks.

MEMBER HASHMI: And just to address the transition component then as a continuation of the hospital --- preventable hospitalization, the transition component could be measured with the readmission, preventable readmission.

Was that what the transition piece was getting at? I wasn't part of it.

MEMBER REUBEN: So, the transition is partly about hand-offs and is partly about what has changed in these patients.

So, frequently when patients go into the hospital and come out of the hospital, they are different than their steady state and those things don't get recognized.

And also, that whole issue is about changing medications. Frequently patients who come in with dementia, they may, you know, they have bradycardia, somebody stops their cholinesterase inhibitor, never gets restarted and know they may have been having some benefit from it.

So, these kinds of issues ---

MEMBER HASHMI: So, it's more than ---

MEMBER REUBEN: Yes. It's more than that, yeah.

MEMBER HASHMI: And possibly could it be a composite measure then so it is a readmission plus medication reconciliation plus a resetting of the person's baseline however we do it?

CO-CHAIR FELDMAN: I mean, another issue that occurs around transitions is the transmission of critical information, you know, whether it's an unstable lab value or whatever it is from one setting to another. And, you know, I think this, you know, it's like transmission of a core set of information.

And I think that CMS is working on --- has been working on for a long time on a core assessment and set of information that goes with the --- in this case, it's a patient from setting to setting.

I mean, I may be speaking out of misinformation here.

(Speaking off mic)

CO-CHAIR FELDMAN: Yes, the care tool. And isn't that supposed to be a common set of information that goes across settings?

MS. LING: So, just briefly, the care tool is a standardized set of data elements that's intended to facilitate measurement, consistent measurement of important domains such as function across different care settings and really then enables that information to be understood as patients traverse from one setting to another.

It is actually that information can travel with the patient, or it can -- that is really up to how providers use that tool.

The focus has been on standardizing the data elements because it's not an instrument, if you will, that is intended to be completed in its entirety each and every time. What is completed is that which is thought to be appropriate at a visit or at a hospitalization.

CO-CHAIR FELDMAN: Thank you. Cille.

MS. KENNEDY: Yeah, Shari, has that been actually implemented yet, or is it still under testing?

MS. LING: It's still in the process of testing and there's a lot of work being done on development of quality measures using those data elements.

Having said that, you know, there is -- some of the data elements actually are already in nursing home, stem from the MDS 3.0 and also from Home Health. So, there's a crosswalk there.

So, even if we're calling it a tool, it's really standardization of data elements.

MS. KENNEDY: And if I'm not mistaken, it's only being used --- well, when it goes into full-fledged use in post-acute care settings.

MS. LING: That is where the testing is currently underway so that, you know, there is a Home Health and all post-acute care settings, we have a common understanding of the domains.

MEMBER GROSSMAN: I just want to insert an element of reality here that I appreciate the --- under some circumstances it clearly is the case that there is communication of information from one healthcare provider to another healthcare provider, but oftentimes there isn't. And some of that lack of communication is, in part, due to education.

So, we get information from --- I get information from folks who are in a nursing home healthcare setting. The nurse brings the information, or the person who is accompanying the patient, brings the information to the office.

But when somebody has been discharged from a hospital and then they are make an appointment to come see me two weeks later, it ain't there.

And it's not there because the information has been given to the family and the caregiver at discharge probably, but the educational piece, why it's important to bring that information to the doctor's appointment for reconciliation of medication, whatever, it's just not there.

CO-CHAIR FELDMAN: Not to mention they may have just lost it. Eric.

Katie.

MEMBER MASLOW: I think that NQF has measures, and I might be wrong, about this -- what information has to go and related to discharge and transitions.

And to me, the thing that is especially important for dementia is to remember that the person with dementia isn't a good historian or reporter of any information.

So, it's really critical that that information get to you because some of your patients probably can report what happened, but many probably can't. And as you said, the caregiver can have the list of new meds or not or anything else.

But I think that in this case if everything that NQF already had on this issue was happening, things would be good even for people with dementia, but that's a big if.

MS. JOHNSON: Yes, and I actually have just pulled up a couple years ago care coordination report. So, there are --- and

Mary probably knows this much better than I do, but there are several measures that look at med-rec, that look at transition having the discharge stuff go from the hospital to the patient going home or going to the next provider and most of them do have lists of certain things.

What I don't know is, you know, should there be something special in there if it's a dementia patient and maybe it's just the idea that they won't remember to bring it to the next person. I don't know.

MS. POTTER: I was going to say what Karen said. Some of the measures are specific to a setting of care.

Like there's a pretty good measure for people who are discharged from an inpatient psychiatric facility that sort of bundles up a bunch of things and sends it to the next setting of care, but if the measure is specific to inpatient psych discharge people, some of which do have dementia, but --

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CO-CHAIR FELDMAN: Though if we have the measures that in a number of instances actually specified the elements of information and the issue is getting the information to the next setting, and if the next setting is the home without any other formal care, then presumably the next clinician who is going to see that person is going to be the patient's primary care physician. Then I guess the question I would raise is, you know, should our committee be saying something like additional specifications or efforts or something need to be made in order to assure that the information reaches the primary care physician. And, honestly, I don't think it's just an issue of people with dementia or cognitive impairment.

People leave the hospital with so many different pieces of paper. It's just not the most efficient way to say that two weeks later if you're lucky, or four weeks later, or six weeks later that's going to end up on the desk of the physician.

So, I don't know if people have thoughts about that, if that's outside of our domain, but the issue --- this comes back to the issue of linkage that we've talked about. Ryan.

MEMBER CARNAHAN: So, I would say that's crucially important that the primary care physician gets it and also that the patient or caregiver is followed up with after the hospitalization.

The highest risk period for adverse drug events is in the first month right after hospitalization. People go out, they don't know what they're supposed to stop, they don't know, you know, maybe why they're on new things.

And oftentimes I know in the world of dementia, people go into the hospital, they get delirious, they get started on an anti-psychotic and six months later they're on that still and there's no reason for it. It should have never been continued.

So, an understanding of why those changes have happened among the other providers who are caring for the person in the outpatient setting is very important.

CO-CHAIR FELDMAN: Okay. So, have we adequately covered this ---- I'm sorry. Mary, I'm sorry.

MEMBER BARTON: I just wanted to build on what Karen had said about other measures that are out there. And it might be something, you know, to stratify.

Like the medical reconciliation measure that's currently endorsed by NQF and is used by NCQA for special needs plans, could be something that you could imagine expanded.

And then in order to draw attention to the dementia population, reported in a stratified way so that that's the responsibility of a health plan that may be responsible for reporting this for everybody who's discharged, but they also are required to report the rate for the denominator of the patients who started off the year anyway with dementia.

CO-CHAIR FELDMAN: Good. Okay. So, with your permission, we're going now to the page, I believe, if I haven't screwed this up, that's clarifying questions, person with dementia. And then it comes down to -- it says, for person-centeredness.

And the question that was raised by the staff is that is it okay to incorporate the work from the other Task 5 project on person and family-centeredness.

And we haven't seen it, but I see a lot of nods here. I think our intention is always not to duplicate the wheel, right?

MEMBER HASHMI: That was material we got in our handouts, yes. So, we've seen that.

CO-CHAIR FELDMAN: Oh, yes. Okay,

fine. So, we're good with that. Okay. Good.

And then the question was, who should be accountable for the --- this is for the detection piece.

So, I --- Joan, I wanted to sort of put the, you know, specifically ask you -- it seems to me yesterday you made some comments about every clinician being responsible in the detection process for asking the five key whatever indicators that might lead you to detection or at least down the road to additional diagnosis. And perhaps I misconstrued what you were saying, but so much of what we have said keeps coming back to the issue of detection.

How does the system know at every level that somebody, you know, has a diagnosis? And that if there isn't some systematic, simple sort of pre-diagnostic set of questions that's going to lead to that work-up and so forth, we're not going to know this population. So, if you could take it from there?

MEMBER TENO: Yes. So, here's the one sort of, you know, this was an issue raised by others yesterday, but, you know, we have someone who shows up in the acute care hospital. They are confused and in delirium. They're not going to get coded as ICD-9 dementia.

I mean, the way we identify populations usually is by administrative data that has an ICD-9 coding.

So, you know, the question is, you know, how do you capture that population in an acute care hospital? It's going to be a little difficult.

But for all other sort of entities that provide primary care practices, you should have an expectation that they are doing some kind of screening on a yearly basis past a certain age, and I'm sure David can give us the AGSF standards on what that age is and I don't --- I'll leave the controversy to you.

(Laughter.)

MEMBER TENO: And then, you know, what you could do at that point is I think you have to link the measures to detection, to then the work-up, and then the onus of someone's got to be accountable for the adequacy of educating whoever within that care team to be educated about the meaning of the diagnosis.

CO-CHAIR FELDMAN: David.

MEMBER REUBEN: Well, I think we have to --- we've been skirting this the past two days, but I think we have to work and address the S-word, you know, the screening word.

And that's kind of the elephant in the room here is that this is one of the very few things where US Preventive Services Task Force is not recommended. You can actually get paid for it through the annual wellness visits. So, we'll see how long that lasts.

But, in fact, I mean, this is

going to be a very difficult sell for NQF, I'm certain.

That's something that the US Preventive Services Force has recently reviewed the literature on and come up with insufficient evidence.

That doesn't mean it's not a good idea, but, you know, it has been a nail in many coffins not only for dementia. The US Preventive Services Task Force comes out and says don't --- since they don't have sufficient evidence, you can't get anybody's attention. You just can't.

That said, you know, when you read actually what they wrote, it says, you know, there are people who probably should be screened and, you know, they can't make a blanket recommendation, but I think we, you know, we have to kind of address this issue.

Do we do screening? Do we do case finding? In what populations? Otherwise, you know, this whole detection thing is very ethereal.

So, when do you screen and who do you screen and how do you screen? There aren't easy answers to this, but the big problem is that, you know, we now have a very heavy foot that says we can't justify doing that.

So, I'm just raising this up. I'm not finding any answers here.

MEMBER COOLEY: This is Susan. My broken record. Another alternative is recognizing warning signs. So, knowing the signs, the public knowing the warning signs and what to do, individuals and families knowing the warning signs, providers knowing the warning signs so that when providers recognize them just like what are the signs of cancer, what are the signs of whatever else when it walks in the door, whenever providers recognize signs and when patients and families report something that is a warning sign, then providers will take appropriate action.

So, that, to me, detection is detection of signs and symptoms. And, you know, I'm starting to think that this needs to have a greater emphasis on the demand side as opposed to the supply side, you know.

The Alzheimer's Association has had a know-the-signs campaign. There's no one set of warning signs that is, you know, still better in others. That's part of the problem -- well, I shouldn't say it's a problem, but adds to the confusion.

However, some set of warning signs, some, you know, core set of things, some change that patients, individuals, families and providers should know about and should recognize, should report, should document and should take action, that's, to me, the whole thing.

It's a difficult thing. The medical system when --- as we recently learned, there are a lot of unintended consequences to even the best-intentioned measures and a lot of ways to get around things in ways that you wouldn't have expected that will defeat the original purpose.

So, that's why I'm kind of --- I'm coming around to this issue if only individuals and families were demanding, like, I demand good care for me and my family is that I think I got a problem and my provider should know what to do.

So, if there were a greater demand, and this again may be unrealistic, we can't get to it, but at least if there were a greater demand, individuals and families coming in to their provider, they, you know, are reporting they are aware of some kind of problem and then the providers know what to do and take appropriate action.

That, to me, would --- I mean, that's my dream system.

MEMBER CORDELL: I will say that, you know, the Alzheimer's Association has promoted Know the 10 Signs for several years.

And, literally, we get daily calls.

Families do go in and say to their doctor, I have a problem. And the doctors do not respond. They say, you're in menopause, you're depressed, you're whatever, oh, you're only, you know, 62, don't worry about it.

So, we do have constant anecdotal evidence that families are using these 10 signs. They are going in.

We hear constantly where a spouse or a child goes in to complain and, oh, I can't talk to you because of HIPAA. I mean, it seems like the healthcare system doesn't want to respond to these queries.

And I think that is something, you know, I'm not sure how you can measure that or incentivize that or I think, you know, anybody that comes in and says, I have a problem, it should be looked at.

And this is where I think, again, with this -- there's so much misinformation about this I rating that some physicians even say, you know, let's not do it at all versus there's insufficient evidence.

And so, even when these patients come in, well, you know, it's not worth screening, you know.

So, it's really something that I think we have to say if somebody comes in and says there's a memory issue, it should just be like, you know, hey, I have a heart, you know, flutter or whatever. It should be addressed and evaluated appropriately.

And I think, you know, we hear it all the time that it's really not --

MEMBER COOLEY: Right.

MEMBER CORDELL: -- unless they go to these really good centers that do respond.

MEMBER COOLEY: And this is Susan again. Primary care is the primary setting where these things need to happen.

It is a provider education and training issue that starts at the beginning of medical education and associated health and

-- the community, everyone is a neighbor. Everyone is aware and alert to changes in behavior that could signal a problem that, among other things, could be dementia. It's not necessarily, but anyway.

So, you know, it's the awareness. It's training of all providers. Starts at the primary care setting. Involves specialists in complicated cases and, you know, it's a --- you say it's a heavy burden, but it's a heavy --- it's a great opportunity for individuals to seek appropriate care.

And at the point that there is a report of a symptom or an observable sign, that's no longer screening. That's just evaluating somebody who has a sign or symptom and you need to figure out what's causing it.

So, the screening is before that. It's people who don't have signs or symptoms. So, that's the controversial part. It's not controversial that somebody has a sign or symptom that you would know what to do, that you would recognize it as, you know, the possibility of dementia as well as possibility of other things.

That's why you have to rule out delirium, depression, normal aging, hearing loss, you know, visual, you know, all the different things that could cause a decline in function that --- thinking and function that someone would observe.

So, I don't know. These, to me, this is a thorny thing, but, to me, it doesn't necessarily have to lead to screening asymptomatic people.

CO-CHAIR FELDMAN: Right.

MEMBER COOLEY: It just -- I'll stop there.

CO-CHAIR FELDMAN: So, I mean, I did jump ahead here. This statement actually says detection should lead to diagnostic evaluation.

And that is the part, Susan, that you said upon, you know, recognition or detection there should be report documentation and taking action.

So, both Katie and David wanted to say something. Is it you, David? Or is it Joan who had her --- go ahead, Joan, and then Katie.

MEMBER TENO: So, you know, I think while we don't have the perfect instrument at this point, I think we all could agree that there should be a process in place. And so, even if we set the bar a little bit low and saying there should be a process in place for screening.

And also, I think the idea of triggers, developing triggers that should lead to screening would be another way of getting access to the population, but I think there is sort of an age where 85 plus should be screened on a yearly basis or something like that, you know, but the point is a primary care practice should have a policy regarding this.

And then I think the second thing is there should be a set of triggers like falls, previous diagnosis of a hospitalization with delirium, med mismanagement, IDLs that all lead to a screening being conducted.

CO-CHAIR FELDMAN: Okay, Katie.

MEMBER MASLOW: So, I think I agree with what everyone has said about this and I think that some people, myself mainly, are broken records on this topic.

It's a huge, huge issue. It can't be looked around and then going forward in a reasonable way.

What the Preventative Services Task Force said is just amazing to me. They said we have good measures for screening. We have nothing to do for people.

There's no evidence that identifying people with cognitive impairment and then going on to --- makes a difference.

Okay. So, if that's where we are right now, then everything else that we've said in this meeting is garbage.

I mean, if it doesn't make any difference, why do anything for people? So, it's just a strange finding that they had.

I think that the -- most people have reacted as if what they said is the --- many of the things that Susan was talking about and that we've debated for years how good are the screening instruments, those kinds of things, that isn't what they said.

So, we have to say something and some people think the magic thing is don't say screening. Some people say the magic thing is don't say detection or use it only for people that never mention anything to their doctor or only people that did mention something to their doctor or --- so, we can't not address this and be reasonable.

We need a way to be sure that people who interact with individuals who may end up with a diagnosis, recognize it.

So, Mark gave this wonderful

example of the AAA doing this work and that they are somehow under the screen of US Preventive Services Task Force.

I think that's really interesting, but we have to do this and it --- in the hospital, we don't have a way to do it. And when people come into the hospital, it's not a good time to try to detect their cognitive status, because almost all older people that go into the hospital unless it's a long-time planned surgery or something, aren't taking meds, they're in pain, they're confused right then. They're going to show up as cognitively impaired.

On the other hand, we know if you ask hospital nurses or hospitalists why isn't this done, they say because the person had cognitive impairment or dementia when they came in, they'll have it when they go out, it's not our area, we only have two days or four days or whatever.

Meanwhile, we know that very bad

things happen to people in hospitals with dementia and the staff doesn't know who those people are. So, they can't do the obvious, good things that would happen.

So, there's that aspect of not just you, all of you people including you AAAs where all -- everyone who cares should be identifying, but there's also and what does it mean? Why is it important to you, you providers, to do this?

It's very important as indicated by all our other measures.

CO-CHAIR FELDMAN: Mark.

MEMBER SNOWDEN: Yes, I wanted to go back to something that Eric said. I don't believe the reason that we have the big problem with diagnosis and it getting communicated has anything to do with the Preventive Services Task Force.

I don't know that most physicians will really decide what they're going to do or not do based on that report. I think it has much more to do with their comfort having that difficult discussion and the time they have that difficult discussion and the fact that they're usually treating a patient with many other problems that they're also trying to deal with in a very limited amount of time.

And so, I don't have any problem really saying that to the extent that screening is taking place and being paid for, annual wellness visits, there are lots of places -- nursing facilities, there are lots of places where this is taking place, if we could get all of those people to do what we really want done, we would set the example for how this could work.

And my belief, and I would differ a little bit with you, Katie, I think if you look at the report, they do try to talk about the evidence that they were looking for. They make a very, I think, cogent comment about medications. They actually say something about caregiver interventions.

And so, I don't think they're only speaking to the efficacy of screening to improve cognition, but I don't think that's the issue.

I think if we could really show through this work that there are other things that will improve the quality and experience, I think they will be more than happy to then say this is why we should now do it. But waiting for that to happen first, I just don't think it's going to happen.

CO-CHAIR FELDMAN: So, I would --- I would like to recommend because we've had some really eloquent language and some deep thinking about this here, that if the group is comfortable in the same way in which we said we would put the core diagnosis and ask the group to work with the staff on this, if maybe we could draft --- Mark and Katie and if anybody else wants to do it, to work on some language that -- for the report that I think that would --- I think that since we are a body and a steering committee of the NQF, it would be --- I think it would probably be advisable that we address this recommendation, this negative recommendation of the task force while at the same time in the kind of eloquent language that you've put, Mark, it gives then all of the obstacles and the other issues and so forth and the different dimensions of what difference means.

If you say it doesn't make a difference, the question is it doesn't make a difference in what.

And just because we have some caregiver, you know, intervention literature that comes out on two sides with regard to how effective some of those interventions are, that doesn't mean this isn't going to make a difference.

I can't believe this researcher is saying this, but she is. So, you know, to really try to draft some language about this because, as someone said, it is the theme that's lurking behind.

And whether we call it screening or detection, I mean, you guys can sort of decide and come back to us with that.

And so, I do --- is the group comfortable with that?

MEMBER COOLEY: This is Susan Cooley. I just want to say I think that there is continued misunderstanding or misrepresentation of what the term "screening" means because it has multiple meanings.

CO-CHAIR FELDMAN: Right.

MEMBER COOLEY: And the actual term, I think, that is controversial is the meaning in which you're talking about evaluating asymptomatic people. And so, the -- and that's what screening is.

The other meaning is to give a brief test. Well, so I use the term "brief test" when I'm talking about a brief test. I use "screening" when I'm talking about evaluating asymptomatic people.

And the thing about the USPSTF report, I think it's a false argument to say that it's saying that there's insufficient evidence that we should do anything.

It's not saying that at all. It's saying it's insufficient evidence to say that identifying kinds of impairment through screening asymptomatic people -- doing it that way, there's insufficient evidence to say that that is better than identifying cognitive impairment through recognition of warning signs.

So, it's not to say that we're going to ignore the problem altogether if we don't screen people. Far from it.

But when I think that -- common sense is that when there are signs and symptoms, that you recognize them and do something about it. Do something appropriate.

So, it's not an either/or. It's screen, or do nothing. And that's, to me, a very unfortunate false argument that has been made in several articles following the USPSTF report coming out.

And, in fact, it's not do nothing, it's, okay, if there's insufficient evidence to support, you know, for or against screening, then at least recognize signs and symptoms when they are sitting in front of you and do something about it. Do something appropriate.

CO-CHAIR FELDMAN: David.

MEMBER COOLEY: So, just wanted to put that in there.

CO-CHAIR FELDMAN: Thank you.

MEMBER REUBEN: Yeah, let me just build on that. One of the unintended consequences of the US Preventative Services Task Force is that the way it's going to be interpreted by physician groups is it's a get-out-of-jail-free card that we don't have to pay attention to this. I think that's the downstream interpretation of it.

It's like, you know, you go in to

talk and say, you know, you've got to recognize dementia, you've got to pay attention to these things.

No, US Preventative Services Force says we don't have to do anything about it. And that's -- it's not the correct interpretation, but that's the interpretation that that's going to -- the message that's going to come out of this and, you know, it's a shame. It's just a shame.

MEMBER COOLEY: Well, there's an opportunity to educate the public and providers on the correct interpretation.

CO-CHAIR FELDMAN: So, Susan, we'll be sure that you have your say over the language of this which will come back to the group as well.

I think with regard to the specific question on this page about detection should lead to diagnostic evaluation and who should be accountable, what would the recommendations be about who is accountable here?

Everyone who is -- anyone who has observed any organized entity or office practice that has detected signs and symptoms?

MEMBER TANGALOS: To try to get that last piece of screening with this piece right now, the way that we've taught -- and actually when I was with the Alzheimer's Association, we -- screening was on the list 25 years ago. It was a long, I mean, it's been on the list forever.

The issue at hand is screening only works when there is enough of the population at risk to make the screening measure valuable, okay.

And what the US Public Health Service was not tasked with and what the Welcome to Medicare was honestly not tasked with is are you dealing with a population at risk?

And perhaps 65 -- I would argue that 65 is not sufficient to define a population at risk, but that patient that was in the hospital with delirium is certainly a patient in a population at risk.

That patient that was hospitalized for a fall is certainly in a population at risk.

And we let the Public Health Services Task Force off the hook and we didn't -- I honestly don't think we made a good decision with Welcome to Medicare, which is age 65 and every year thereafter if and when you define a problem, which means I don't want to define a problem.

So, I think we -- as we still go forward, we have to be cognizant of populations at risk. That's where the warning signs fit in. They are defining a population at risk. And those populations at risk are what need to be studied.

I'll give you an anecdote. 20 plus years ago I was on the board of a senior high-rise that was just overwhelmed on the nursing home side and couldn't sell the apartment community and we would screen people coming in by asking qualitative questions.

We'd ask the doctor, how's Uncle John doing? We'd ask the family, how's Uncle John doing? And they would give us the socially-correct answers. Well, you know, he's slowing down a little bit, but, you know, it's -- he's okay. He's just -- it's just time to move.

I got news for you. There is never a time to move that isn't predicated by an at-risk situation.

And we kept admitting these Uncle Johns into the high-rise, and within a week they were banging on everybody's doors, they were peeing in the hallway and they were moved into the skilled nursing home.

I finally said, you know, let's put an objective test when Uncle John comes to our facility, and all we did was a mini-mental status examination.

The docs weren't lying to us. The families weren't lying to us. They were giving us socially acceptable qualitative answers. And we said give us a quantitative statement on what this person's like, and we washed out all of these people that wanted to get in the apartment community just because it was time.

CO-CHAIR FELDMAN: So, are you addressing this question here of what type of measures would best get at this concept?

MEMBER TANGALOS: Actually, I think so. I really think that we've talked a lot about that engagement where it occurs. We spend a lot of time talking about warning signs right now and I think we can craft something that says when a patient -- when a patient is identified at risk, something in the healthcare system has to take action.

And we've hit a bunch of them. We've hit medication management. We've hit falls.

When I was recruiting new cases for our registry 30 years ago, the desk personnel would say, Dr. Tangalos, we have someone that missed their appointment. And I would enroll a new case. More often than not, I would enroll a new case.

MEMBER SNOWDEN: A couple things. I think the at-risk populations that you just mentioned and that Susan was mentioning is exactly what our group yesterday with Number 22 over there was trying to get at.

I don't know that we articulated it on the board well enough, because I think that -- my blue dot is the only one that's there, but that's exactly what we were trying to say that there are identifiable people where detection/screening would have a much bigger payoff than in the asymptomatic.

MEMBER COOLEY: That's different though. This is Susan. That is different from people who are showing warning signs.

MEMBER SNOWDEN: That's true.

MEMBER COOLEY: So, at-risk, that's the same thing.

MEMBER SNOWDEN: That's true.

MEMBER COOLEY: That is not the same thing as already showing signs and symptoms.

MEMBER SNOWDEN: That is true. That is true. My sense around who's responsible or accountable for detection, I think, is going to be pretty broad.

I think there are clearly in my world, there are clearly community-based organizations, Home and Community Services being the biggest, that should play a role in this.

I think it's unconscionable that they do this and don't tell people the results of their assessments.

To the extent that the annual wellness visit is here, I think it will provide a financial incentive that's the exact opposite of I think what David has said.

I think you're right. A person who doesn't want to do it may look at the US Preventative Services Task Force, but the money tied to the annual wellness visit I think will draw a lot of people into now doing this and that they should be held accountable for this detection rate as well.

CO-CHAIR FELDMAN: Susan, I wasn't sure whether your comment was converging toward agreement or disagreement again.

I think that this group is really struggling with this issue and I'm not sure that we're going to reach consensus here. But am I right, Susan, that you were beginning to -- I don't think you were moving toward agreement here, but maybe I misunderstood.

MEMBER COOLEY: I was not, because I still would make a distinction between risk factors, people at risk, groups at risk versus people who are showing signs and symptoms.

Risk factors, I was looking at, you know, one of the articles that people are talking about right now on dementia screening indicator. Risk factors such as -- and this is Deb Barnes and colleagues -- age, education, strokes, history of strokes, diabetes, body mass index, requiring assistance with money or medications, depressive symptoms. So, those are a variety of things.

One of those in there, requiring assistance with money or medications, is what I would consider a warning sign. A sign or symptom.

The type of things that we have in our list of warning signs are things that providers might observe, that patients might report, and there's a list of those like, for example, being a poor historian, unable to give a coherent history, failing to keep appointments at the right time, repeatedly and unintentionally -- family unintentionally failing to follow directions like on medications, explain to the caregiver or family member to answer questions or that the patient or caregiver might report that the person is asking the same question over and over again, becoming lost, not able to follow directions, confused about time, people, places, blah, blah, blah.

So, the latter group are things that are warning signs that clinicians may notice or patients or families might report. That's pretty different from an at-risk population. They're at risk because they've had a stroke or because they have had multiple hospitalizations where they have a history of this, that or they're a certain age.

I mean, that's a population at risk and you can come up with different risk indicators, but that's still saying we want to -- that's, to me, like screening light. It's like instead of screening everybody who are asymptomatic, we're going to screen a certain group who have high risk.

And to me, that's an emerging

area, but there is -- it's complicated. I myself don't even understand all the things about how do you use risk factors and how -- what is the positive predictive value of these different risk factors and their combinations?

It's very complicated to me. I mean, I truly would like to know more about it, and I don't. And there are protective factors that we don't -- perhaps we know about or don't know about, but it's not all just about risk factors.

I mean, the risk factors is one thing, and screening a high-risk group is a type of screening. Screening meaning evaluating asymptomatic people, people you don't have a reason to think they've got a problem with their thinking and screening.

The other side which is the detection based on person already having signs and symptoms, signs or something that they or the providers would observe or that the patient would report symptoms, that's the part that, to me, is not controversial in that if we could get providers and individuals and families to at least address people who have symptoms, you know, that would be good, you know, aside from the issue of let's look for people who have cognitive impairment even though there's no overt signs, that's the screening side, you know.

Do that or not, but couldn't we at least try to improve dealing with people who actually have signs and symptoms and they are for whatever combination of reasons ignored when they are sitting right in the room with you.

CO-CHAIR FELDMAN: so --

MEMBER COOLEY: So, yeah, I was not -- I was not converging on agreement.

CO-CHAIR FELDMAN: So, Susan, there was one card up when you started this, and then there were a flurry of cards that came up.

And, I mean, if people -- Mary was

the one whose card was up. And if others would -- unless you feel it's totally unjust, if we could let Mary have her word here and then agree that this is really problematic that there are conceptual issues, there are terminology issues, I think we're all -- we have different concepts of risk and symptoms and that I just don't think we're going to resolve it at this moment right here and that we need to move on.

So, Mary.

MEMBER BARTON: Thank you. I would just say so I appreciate the difference and I'm glad that you brought that up, Susan, the difference between screening asymptomatic people and what -- my term would be case-finding, how you treat the other sources of information that trickle into your office and into your visual inspection and into your auditory experience of the patient encounter.

And yet having recently reviewed the literature on this for the purpose of trying to design eMeasures for CMS, many of the things that we have talked about that have logical sense and they're comforting and there may be one or two studies that have shown a risk factor in the range of, you know, two to three and a half, which is not enough of an odds ratio to really distinguish a population, unfortunately, there are -- I would say that there are two tools that have been created that neither of them have been replicated, to my knowledge, and only one of them is probably feasible for use in primary care, that tries to string together, you know, an index based on these kind of risk factors that might be knowable from history.

And so, I think that the research world could be -- there is a place maybe in this report for us to lay out where we think the evidence gaps are most -- it's not low-hanging. I guess it would be intermediate fruit.

CO-CHAIR FELDMAN: Right. That

would be real gaps, right.

MEMBER COOLEY: I would agree.

CO-CHAIR FELDMAN: Great.

MEMBER COOLEY: Emerging area definitely important.

CO-CHAIR FELDMAN: Thank you. So, we are -- we have actually a bunch of issues in our parking lot.

I think we've discussed one of the most complex ones just over the last 20 minutes or so. So, I'd like to shift gears a little bit.

You have a slide. I think it's Number 64. Yes, is that this one? Yesterday's -- it's titled Discussion of Yesterday's Parking Lot.

And at the top it says, Types of Measures, Social System, Population Measure, Structural Measure.

People go that? Okay. So, I think we should try to plow through these issues. And if there are areas that we think we have touched upon already and that we can just move on, we should do it.

But if there are areas where we think we identified an important area, but there are still important points that we want to make, I think we should.

So, at the very top of this is the topic of social system and population measures. And we started out our meeting this morning with some conversation about we shouldn't think that we're excluding these.

And certainly some of the measures we've discussed already, for example, hospitalization rates, could be developed at the population level, but are there probably other comments about population measures and social system measures that people want -- may want to add to this discussion if we haven't worn you all out.

Razia.

MEMBER HASHMI: Just a quick comment. From my perspective, the discussion about community -- agency and community measures covered it for as far as social systems are concerned.

CO-CHAIR FELDMAN: Do others, I mean, I think there was generally the sense in the room that one aspect of, you know, like talking about community capability or dementia capability, that definitely the community level was an area in which that could be assessed.

We haven't -- we have something to read about this and we might want to lay out some of the other measures that would go in there, but I think we also thought that another aspect of that was thinking about -- that health systems also could be -- should be dementia-capable as well.

Are there other specific population measures that people had in mind? We talked about, again, about hospitalization. Others?

Razia.

MEMBER HASHMI: It's me again. You know, this is a unique clinical condition that requires some unique solutions and, therefore, unique metrics that maybe don't fit in the biopsychosocial model that we consider for other clinical conditions.

And so, while I don't have the answer, when you ask the question about what other population measures, I would say we need to think about sort of nontraditional population measures.

Again, I'm not smart enough to know what those are, but beyond sort of the debate that we've had about US Preventative Health Services Task Force and sort of the medical lens. This requires a non-medical lens, in my view.

And so, those kind of population measures, I'll think more about it and tell you if I come up with one.

CO-CHAIR FELDMAN: And I -- it seems to me this is probably an area for structural measures as well.

I think one question I have is how advanced the science is. So, for example, you know, thinking about community capability, I think of the whole movement around age-friendly communities.

And there are various initiatives and various measures and many of them are structural to identify the age-friendliness of a community.

There is the AARP Commonwealth state-level -- what are the indicators called? I forget the --

MEMBER FRISS-FEINBERG: It's the State Scorecard.

CO-CHAIR FELDMAN: Yes, State Scorecard, right, of state capacity to provide home and community-based services and they -- essentially a long-term care -- it's long-term care capacity, really.

MEMBER FRISS-FEINBERG: Right. It's the performance of states. What are the measures and indicators of the high-performing state system of long-term care. Long-term care being from the family home to the nursing home as we talked about yesterday.

And the second scorecard will be released on June 19th on Capitol Hill and it does include measures of support assessing and addressing the needs of family caregivers as an indicator of a high-performing state for long-term care.

CO-CHAIR FELDMAN: The thing about the report card is that it does rely on existing measures that have been widely used and presumably validated and on publicly available data.

What it does not do -- it identifies many dementias around -- like around caregiver capacity that would be relevant to us, but it -- they're generic. They're not specifically geared to dementia-friendly, but that might be something where we might want to point direction in terms of --

I guess you'd call them structural measures.

MEMBER FRISS-FEINBERG: Yes, I would agree that if there were good measures in that regard for dementia-friendly communities or however that is determined, decided that that could be part of the scorecard in the future.

CO-CHAIR FELDMAN: I think this is a tough area for us to address.

Katie.

MEMBER MASLOW: One thing that I was talking to Jane Tilly about and I think both of us think it's not NQF ready yet, but the states that have received these systems integration grants from ACL have been looking for ways to measure whether their state is dementia capable.

So, detection is one way. And they struggle just like we've been talking about, about how to do it. One way is training. Is training available widely to different people?

And then I think the third right now, Jane, correct me if I'm wrong, I think it is, is there a system for referring people to the right -- to dementia-capable providers?

Do you think so? We can get that to you.

MS. TILLY: Yeah, what I was going to -- whoa. I was going to say is I just don't remember what the -- I'm a little more fuzzy on what the second generation of thinking is with dementia capability states.

I would mention that for the purposes of the Committee, Minnesota is a state that has a long history of doing wonderful things in these Alzheimer's Disease supportive services programs and I believe they have got a lot of the dementia capability elements in place now and they have dealt with identifying people and measurement issues.

So, it's probably worth a phone call to some folks there.

CO-CHAIR FELDMAN: Uh-huh. So, if

that could be part of our environmental scan, that would be useful.

And I would also remind people I tried to write it down verbatim and I didn't get it quite verbatim, but before Eleanor left she made a very strong statement.

She said, it is an imperative that existing community-level measures be adopted and/or adapted or, if necessary, new measures be developed to advance quality monitoring and improvement at the community level.

So, you know, recommending a very strong statement in the report as that -- and then we also had a level -- we had a conversation about dementia sensitivity at the organizational provider level.

And remember we were talking about things like scheduling, physical space. What would other elements be that we might recommend there?

MEMBER REUBEN: Yes, there's a lot. I mean, what tends to happen with patients like this is that unless there is an empowered, generally, daughter or caregiver, that these patients especially when they go to non-primary care settings, but also primary care physicians, they get shuttled in, shuttled out and examined like meat and, you know, look at your arm, look at your shoulder and goodbye and, in fact, their real issues aren't addressed.

So, there has to be some kind of both sensitivity training and actually perhaps some kind of different pathways for these people. And also to make sure that there is somebody who can speak for them at that visit.

CO-CHAIR FELDMAN: Right. Like a setting-specific advocate or a navigator just to get them through the system. So, I suppose this is an area where there probably is a big gap.

Katie.

MEMBER MASLOW: I think it would be important to have Eleanor's feedback about the dementia-capable concept. So, are we looking at two concepts, or one here?

To me, dementia-capable means dementia sensitive. That's part of being dementia-capable. But she might not feel like that and others might not feel like that, too.

CO-CHAIR FELDMAN: Right. And also it might -- the measures could well depend on the level at which you're measuring.

So, you might say that at the community level you would want provider organizations that were, in a sense, you know, centers of excellence or, you know, capable of -- or not centers of excellence, but routinely capable of, you know, of doing certain things, but then you would want to measure down at the organizational level specifically whether those things existed and/or whether they were doing them.

David.

MEMBER REUBEN: I'm still not going to try to speak for Eleanor, but there are kind of a couple different levels here.

In fact, this evening I'm meeting with folks about dementia-friendly communities and trying to take what we've learned in England and try to have some sister cities here.

So, if anybody is interested in being a sister city with England -- but part of that is actually, you know, just kind of the organization of services.

So, and they kind of tend to focus on certain things like transportation. So, are there for demented people, are there people who can get them on the bus and off the bus and make sure they don't get lost, dementia-friendly cops, you know, those kind of things, who has some kind of awareness. Local community services, but you can't do it all at once.

I mean, it's kind of a roll-out. You do one thing, then do another and you have some kind of a commitment.

So, that's actually kind of dementia-friendly. It really says we've got an issue here, we're going to -- as a community, we're going to deal with that.

In the healthcare system, it's really different. In a healthcare system, it's capacity, it's capability and saying that are you really able to care for this population or should they be moved to a different hospital or different healthcare system.

And there, I think it's really much more proactive. It's not just saying, you know, the structure is in place, but the processes are also implemented. So, the bar is higher. The bar is higher if somebody is actually taking care of patients.

That would just be my two cents.

CO-CHAIR FELDMAN: That's an interesting notion about the level of proactivity and also the distinction between structural and process measures here.

Are there communities -- one second, Lynn. Are there communities in Great Britain that are measuring what it means to be a dementia-friendly community? You can find that out tonight?

MEMBER REUBEN: There are some. And, you know, it's interesting. It's much more a theory than it is a practicality. It's kind of like what we heard yesterday about how we're going to fix this problem.

But the -- and there are a couple places that are trying things and there are a couple small communities, but it's not -- it's not mainstream. It's not like -- it's not like everywhere. It's not like don't go to Britain and become demented.

CO-CHAIR FELDMAN: Lynn.

MEMBER FRISS-FEINBERG: But isn't it also, David, reimbursement for healthcare providers, too, that physicians are not necessarily reimbursed for talking with the family and spending that time for a family consultation and how that could change the whole trajectory if there was adequate reimbursement for looking at the person in the family as a unit and talking with that family member as an informant to help in the diagnosis of the person with dementia?

MEMBER SNOWDEN: Well, there are some work-arounds here. I mean, what you can do is you can actually up-code by using the counseling modifiers. And we do this. We do this and we put a little thing at the bottom saying, you know, greater than 50 percent of the visit was spent counseling and discussing with the caregivers, but you're right. You're right.

If there is money associated, doctors -- that changes doctor behavior quickly.

CO-CHAIR FELDMAN: Katie.

MEMBER MASLOW: I don't know this, but we talked yesterday about the Minnesota dementia-friendly communities. And I know that there is an evaluation happening. And I'll ask the evaluator and let you know whether they are -- whether the evaluation has standards in it. So, are they evaluating for certain characteristics or not?

They have about -- I think they have 22 now and they've got $750,000 from Blue Cross recently to, you know, to add 20 more. So, they may have criteria, but I'll let you know that.

That wouldn't be the same as a measure, but it would be a start in thinking about it.

CO-CHAIR FELDMAN: Great. I was just noticing that under the next bullet on the clinical and community systems link there's a little notation about education.

And our group yesterday definitely considered community awareness or community awareness activities, campaigns or whatever to be an important part of a dementia-capable community.

And we've spent a lot of time this morning talking about creating more information on the demand side. And on the family and person sides, greater awareness and less stigma about making demands on the system.

On the clinical and community systems link, we've had a variety of discussions, I think, about this. I'm not -- do people feel that we've covered it adequately?

What's the main point that we really want to make here or the main points?

MEMBER MASLOW: I think the main point is it's critical. We have to have a link there and then there's a lot of difficulties, right?

CO-CHAIR FELDMAN: Mark.

MEMBER SNOWDEN: Yeah, I was going to say the same thing. I think David made the good point that they often run independent circles and they need to overlap a bit more.

I would also add accountability at both levels.

CO-CHAIR FELDMAN: I would -- right. And I would add something about -- and, again, this is probably in a recommendation, not in a measure, but that payment systems, government contracting, accountability measures to the maximum extent possible would build in incentives for community provider -- community clinical systems links.

Okay. The next one. Weighing importance, evidence and practicality and prioritization of potential quality measures.

What did -- do you recall what prompted that?

MS. JOHNSON: I think it was the question, really, and David can help me out, but I took it as a lot of these things that we've talked about are aspirational.

So, what's our short term? And, David, do I have it right?

MEMBER REUBEN: So, the deal is it had to do with prioritization. That's where it came up was how do you prioritize? What are the criteria?

But since we've completed that exercise, actually the deal isn't done yet. Because as NQF or whomever moves forward with this, there are a lot of things that are -- we've recommended that there isn't the kind of data that typically go into NQF-approved measures. So, important, but not approvable, so to speak.

Then there's the ones that there is evidence behind, and they may not be as important. They may not be as important or they may not even be relevant.

And then there's this whole other construct of practicability. It's whether you could actually do something.

I mean, in other words, you can actually measure these things. Are they measurable?

So, for example, one of the things that came up was maintaining function. And that's a really difficult thing to -- a concept to measure as a quality indicator.

It can be done, but it's a lot of work. So, you know, these are about -- nothing threads the needle and fits all three of these things.

And the question is, how do we -- hoe do we weigh them? And, you know, from a clinical perspective, what's important clinically is my top priority, but that may not be NQF's top priority.

CO-CHAIR FELDMAN: That was a showstopper. I mean, I think there is certainly always concern in a group like this that ultimately the measures that rise to the threshold of evidence will not be the ones that were the most important to the group.

And I'm not sure what the strategy is for dealing with that other than to say in a report we've identified six things that we believe are of the utmost importance and the evidence doesn't rise to the level that's required for formal endorsement of a measure. And, therefore, we recommend that additional work be done to create this into an evidence measure.

We talked about this a little bit earlier this morning about recommending certain measures to go into the pathway to become a performance measure.

Is that how we would handle that here? I mean -- Katie.

MEMBER MASLOW: I think yes. And I think that NQF does a good job on that. So, the framing, I think that I feel like in the last day and a half we've sort of come together about a lot of the important framing issues. I hope you feel like that.

And then, that we don't have enough evidence to support a measure, just has to be said.

And then I was excited about what

Deb was pointing out in terms of this coming from the ACA and really letting us look at gaps and look at where more measurement development is needed.

Those are real opportunities for us to deal with. We want to measure something, but we don't have a measure that will pass the standard. So, I think we're in good shape, I mean, as good as we could be.

CO-CHAIR FELDMAN: Mark.

MEMBER SNOWDEN: I think my take on this is that you can certainly ask our opinion as a group about these things. And to me, the one that's the most important is actually the importance one.

I think it could take a lot of time for us to really agree on what's the evidence or not. And for a measure that's not developed, the feasibility may be hard, but I think we could certainly give you our opinion on what's important or not.

The second take I would have, and

I would say this about a lot of the measures that are being, I feel, thrust upon me as a provider, is I would love for someone to be able to show me at some point especially how the process measures have done what people have said, because I get asked to record on our QI initiatives.

And one of the questions that a very astute person in the audience asked me is, okay, so you've achieved the 90th percentile in doing what you were asked. Do you really think it's made a difference in your patients' lives?

And I had to tell them that I have no data to answer that question.

MS. JOHNSON: And we'll just put in a plug there for outcome measures because, you know, the outcome measures are what is important to patients and we don't really need an evidence base for those issues.

CO-CHAIR FELDMAN: Well, they are the evidence base.

MS. JOHNSON: Yes.

MEMBER TENO: I'm struggling with what you were getting at, David. I was wondering if you could take another crack at it because the example that you had given was more of the ability of that measure's response to change.

So, I was wondering if you could take another crack at your point so I could understand it.

MEMBER REUBEN: At the importance part, or all of it?

MEMBER TENO: Well, what you really want to accomplish.

MEMBER REUBEN: Okay. So, if we go through and I was actually hoping can you go back to the ones that we kind of agreed on? It was 31 -- the one with 31, 25 and all those. That slide.

(Pause.)

MEMBER REUBEN: I think the first thing you started with this morning. Yeah.

So, you know, the bad news here, the bad news here is that almost none of these are going to get through, okay?

This is what we settled on. We settled on -- these are the things. And if you're going to look for evidence base to support these things, guess what. We kind of wasted the past couple days.

So, the conundrum that's here is that there's a lot of stuff that we through clinical experience and whatever know are important.

But the fact is just like the US Preventative Task Force is that the studies haven't been done, the questions haven't been asked right -- correctly or the evidence just doesn't show it.

So, are we going to advocate for things that have been shown and the number of quality measures are going to be much fewer. And then they -- I'm not going to say trivial, but let me just tell you a lot of the PQRS measures are trivial, you know. They just don't make a big difference in the world. So, that's the importance versus the evidence one.

And then the practicality stuff is some of the stuff is whether; A, can it be measures, and; B, is it responsive to change?

So, that's kind of what I'm getting at. It's really, you know, what are we trying to do here?

Are we trying to come up with, you know, a small number of really good evidence to support recommendations that really don't do much if they're implemented, you know?

Screening a 90-year-old woman for osteoporosis and -- give me a break, you know.

CO-CHAIR FELDMAN: Joan.

MEMBER TENO: So, I'm not worried about the evidence base for some perceptions of quality of care.

I've done a couple NQF applications. I've found it really easy to give citations and do that.

Second, just to go in a little bit of haphazard order here, I don't -- I have not seen really responsiveness to change be a make-or-break measure on a measure -- or a make-or-break criteria on a measure.

Thirdly, I actually think we're coming up with a list of areas for development of new measures.

So, in that validation of that new measure and in developing that measure, you're going to get some of your justification based on that work.

I think the biggest barrier to all this is how are you going to fund it, okay? And, you know, as someone who has developed a measure, a lot of the work on that measure was done on weekends and for free, you know. It was only much more later into the course was it done.

So, I don't know if I'm as worried --

MEMBER REUBEN: Well, just to

counter that --

MEMBER TENO: Sure.

MEMBER REUBEN: -- how many dementia measures have gotten through NQF?

MS. JOHNSON: I think right now we have five.

MEMBER REUBEN: Do you remember what those are?

MS. JOHNSON: Actually, two of them are practically the same. They're set in the nursing facility and they're looking at diagnosis, trying to give a diagnosis in NFs based on answers to BIMS in the MDS. I feel like alphabet soup here. So, that's two of them.

There's an anti-psychotic medication one and --

SPEAKER: That's in nursing homes.

MS. JOHNSON: That's in nursing homes as well. And I'm blanking on the other -- actually, there's only one more and I'm blanking on that one.

MEMBER REUBEN: So, out of all the stuff we've talked about, it's like nothing even close except in the nursing home population.

MEMBER TENO: But how many have been rejected? I think the issue is not --

MEMBER REUBEN: A lot.

MEMBER TENO: Really?

MEMBER REUBEN: Yes.

MS. JOHNSON: Yeah.

(Speaking off mic.)

MS. JOHNSON: The AMA ones went down.

MEMBER REUBEN: ACO, all these things have been put together and are evidence-based ones.

MS. JOHNSON: And those were process measures and many of them had to do with assessments.

MEMBER TENO: Okay.

MS. JOHNSON: Which we all agree are important, but they're very distal to that outcome.

MEMBER TENO: So, I still wouldn't translate that experience into coming up with a patient experience measure.

I think -- a good patient experience measure, I think, would have to -- you could build a very strong case. You have to think very carefully how you're getting the denominator. You would have to get the CAHPS folks over their hurdle of being afraid to talk to someone other than a patient, but hopefully we're working on that right now.

We have been talking to brief family members. So, that's a start.

MEMBER REUBEN: That's only one small component of what we want to do here.

MEMBER TENO: Sure.

MEMBER REUBEN: I mean, that's the conundrum. The conundrum is the kind of measures that measure this kind of stuff aren't getting through. And that's a problem.

MS. JOHNSON: Although, I would

say, I mean, like even with the support, the training, one easy process measure might be did you offer training, you know. And that may or may not get through.

But if you ask the caregiver their experience, did you feel that you had the skills that you needed to, you know, to take care of my loved one, that kind of measure probably will get through.

So, I think some of these concepts, you know, maybe it's creativity in how you construct the measure.

MEMBER TENO: I think the other thing that really needs to happen is how do you get the measure developer connected with the healthcare system to really do a good measure?

To me, what's really lacking in the whole process is the ability to do a multi-site study where you can measure what's called the ICC -- measure of the ICC so you understand how much variation and how many cases you need to do to have that.

And that's the one thing it's really hard as a measure developer to do that, because that means you're really going beyond a small validation study, but you're going to, you know, where you're going to get 30 or 40 healthcare institutions to do that.

And that, unfortunately, is a sizable chunk of change to do that. It's not easily done and it takes really monetary support to do that.

CO-CHAIR FELDMAN: So, I'm probably overly optimistic. But given the ACA and what I think are forces from many different parts of the system, I guess I'm cautiously optimistic that the likelihood of, frankly, federal dollars to develop some kind of composite support of caregiver and some kind of composite-shared decision-making could for a caregiver person with dementia and, you know, could actually reasonably come about.

And if we're talking about gaps

and we're talking about where we would put our money, we have a couple of person-reported sets of, you know, I don't know whether, I mean, we put it in terms of a composite measure to really think about the components of such a measure.

I mean, I think that that's potentially where this could lead if we wanted to be very strong in our statement because we said we were talking about gaps.

MEMBER TENO: Just occasionally I wake up here and comment a lot. I'll try to make this my last comment.

The other really low-lying area here is to look at some of the existing measures and see if you can create a stratified analysis based on that.

So, I think the perfect place to begin and to publicly acknowledge, I actually think the 30-day hospital readmission measure was brilliant. It really had a huge impact on our healthcare system when you have healthcare systems now saying I'm going down from working with 90 nursing homes to only 60 nursing homes.

So, you know, you could develop a measure that would really get at dementia patients 30-day hospital readmissions that just puts us on the radar and to look at it as stratified. So, I think that's another opportunity.

It's a low-lying fruit. You can do it. It's already an existing measure. We just now bring it up to prominence by reporting it.

CO-CHAIR FELDMAN: And we have consideration of existing measures and exclusion, slash -- I think of it as both inappropriate exclusions and important inclusions and stratification.

And so, we have identified -- yesterday we talked about CAHPS and the -- we talked about pain measures. We've talked about transitional care measures. We've talked about the experience of hospitalization.

Hospital readmission measures are having a big impact, as Joan said, on the hospital system.

There are also hospitalization measures in nursing facilities and in-home healthcare.

I mean, those are all areas where if we stratified for the population with dementia, it could have an impact.

And where I think it would also in some of those create a strong incentive to actually record the diagnosis, because then they would be stratified and, you know, so -- and compared against other people with dementia.

Murray.

MEMBER GROSSMAN: So, this may be -- this is clearly a question of ignorance and this may not be the right place for me to ask it, but it sounds like we're trying to figure out what kind of content is going to go into a report.

And I'm trying to understand if part of that report includes something about the payoff. Why are we doing all of this? We're going to save X billions of dollars a year because we are screening, we're going from diagnosis -- from detection to diagnosis, that kind of thing.

Does this report intend to include something about payoff?

(Pause.)

MEMBER GROSSMAN: Sorry. I can ask afterwards.

MS. JOHNSON: I would have no idea what --

(Speaking off mic.)

MEMBER GROSSMAN: Yeah, this, I mean, this is totally out of ignorance, but the point is we're trying to find some source of funding so that we can develop measures that we all think is needed. And so, we have to convince somebody that that is a useful thing.

And to do that in this day and age, oftentimes it comes down to dollars and cents.

So, how much money are we going to save the government by investing some money now in developing these measures?

MS. JOHNSON: I think in general I was not expecting this report to try to figure that out and I would not even know where to start, to tell you the truth, on an ROI or something like that.

My interpretation of what HHS has asked us is that if they should have money in the future, where would they want to put their dollars?

So, we're kind of going on the assumption that eventually somebody will want to put some dollars into this and we don't have to make that case.

MS. POTTER: But I would remind

everyone that the National Healthcare Strategy has as its sixth goal, the one that gets forgotten all the time, affordability.

So, you know, that's part of what the Department and the ACA think about in terms of healthcare quality, you know.

You may not use it for quality improvement, but you might use it for accountability.

So, I'm not saying that what Karen said is not what would be included in the report, but just that the affordability is something that should be thought about, that's all.

CO-CHAIR FELDMAN: Ryan, and then Barbara.

MEMBER CARNAHAN: Yeah, I just wanted to put in a quick plug for the high-risk medications measure as one to be stratified, because I think it's doubly or triply important in this population. I mean, you could add a few meds, but for the most part it's a pretty good list.

MEMBER BAYLIS: So, I'm concluding that NQF will most likely approve outcome measures rather than process. Is that what part of that discussion was with David and some of the things that I -- outcome rather than process?

(Speaking off mic.)

MEMBER BAYLIS: Okay. And then also the other point is -- it's on. Okay. And the other point is about the evidence base.

So, should we sort another sort of what measures are processed, which ones are outcome? And then who will do -- who will research and find the evidence? And what strength of evidence does NQF typically look at? IT's like A, B, C or whatever.

Is there something that is a standard for them and will we do that, kind of sort outcome and structure or process?

MS. JOHNSON: Well, I think some of

the questions that we've already talked around has gotten to some of that already.

In terms of finding the evidence base and all that sort of thing, that's into the realm of the development just like, you know, we're not asking you to specify all of the things.

So, what we're hoping for is the concepts and some direction in terms of, you know, should -- can this be an outcome measure, or does it need to be a process measure?

Any kind of input that you have on that, but then it would be the developers who would do that actual specification and finding evidence if they need it for process measures, that sort of thing.

CO-CHAIR FELDMAN: I'm sort of pondering this notion whether one of the sentiments we want to express is that without, you know, short of some cost benefit or cost effective analysis, but some kind of statement about, you know, identifying people with dementia and seeing that they get appropriate care over the, you know.

And one has to be cautious. Because as David said, you don't want to imply that people should never go to the hospital just because they have dementia or whatever, but, you know, there are certain kinds of procedures and all kinds of things that, you know, that are probably not advisable for people particularly with advance dementia.

And greater attention to identifying and providing appropriate care for people with dementia is not only good for the individuals and families involved, but will have -- will have affordability benefits, you know.

And I don't -- I think particularly end-of-life and advance care and, you know, advance care planning, I mean, this is kind of soft, I guess, to put in the report.

MEMBER TENO: I don't know if we have to make a business case for the measures right now.

You know, I think all we're trying to help people is to think through where there is gaps in potential areas that we as an expert group of clinicians and scientists and various other roles think that it would be promising to consider.

I think as you go through this process of measurement development, you know, and if you want to go to national implementation, you end up as one of the things you have to do -- to become compliant, you have to go through a review process where you have to cost it out and say how much this is going to cost healthcare providers.

CO-CHAIR FELDMAN: All right. We're just about -- it's just about time for us to take a short, you know, pick up lunch and then come back to finish our discussion.

We have a variety of other parking

lot issues. Some of which I think we've really touched on directly or indirectly like delivery system change and its relationship to payment systems and publicly reporting.

We've talked about patient-reported outcomes. We've talked about use of non-dementia-specific measures. We had a lengthy discussion of safety yesterday.

I think we have not come back and it didn't -- it's interesting it didn't really surface in our priorities to the issue that was raised early yesterday when we were discussing vignettes, which is you can have this great measure around, you know, participatory and shared decision-making -- it's the issue of personalized measures. That you can have all this discussion of individualized goals and shared decision-making and so forth. But if in the end the performance measures aren't in accord with individual goals, then a system or an organization or whatever is being measured on a set of things that, in fact, are not in alliance with what people want.

And I don't -- this is, it seems to me, the last really big issue that we talked about yesterday that we really haven't come back to at all and isn't really -- I don't think it's reflected in the -- our priorities because we've put a huge emphasis on the shared decision-making and so forth, but we haven't really -- but you could measure that without necessarily changing the other outcome measures that are there.

So, I don't know how people want to -- if people want to take that on in some way or not.

MEMBER REUBEN: Yeah, I think we have to take it on. I mean, I think -- I think we have to take on a new outcome measure.

I think we have to take on a new outcome measure of goal-oriented care for patients with dementia, you know.

It's just in an area where existing outcome measures don't really -- aren't really appropriate or relevant.

MEMBER BARTON: Don't apply.

MEMBER REUBEN: They just don't apply. And I think that can be done. There is a science behind doing it. And I think we're shortchanging our patients if we don't, you know.

The idea is it's not how many -- it's not like glycohemoglobins. It's kind of this is your life. This is the last part of your life. What do you want from it?

And if we don't establish those outcomes and measure how a system does, performs on that.

So, they have to be individualized. They can't be generic outcomes.

CO-CHAIR FELDMAN: So, you and I spoke kind of fervently about that yesterday, but I don't think we heard a lot from other people. And it's also the issue of how you would aggregate it up to the organizational level.

So, I think it's important that we just get a little bit of a sense of the group here about this.

Mary.

MEMBER BARTON: Well, I'm fervently in favor of this. And I think that, you know, one of the questions, maybe one of the ways that this group could assist in this trajectory is to find, you know, either a tool or a couple of tools that have the relevant domains in them that you could use to repeatedly administer. And then help in a shared way, discuss with the patient and the caregiver, which one of these matters to you, so that you could then individualize the goal.

And so, I think that where the starting point, people are like throwing up their hands, they don't even know where to begin. And having either, you know, if there's a favorite tool that geriatricians know is the one that works, and I'm not a geriatrician, I don't know, or if there's a few tools that are practical to use in that kind of setting, double bonus if they could be used at home by the caregiver on their mobile phone before they came to the visit, right, and that that would be a big contribution of a committee like this to then getting developers like me engaged in trying to make measures like that.

CO-CHAIR FELDMAN: Lynn.

MEMBER FRISS-FEINBERG: As I think some of you know around the table there's been an enormous amount of work in thinking about the importance of assessing the family caregiver's needs.

What hasn't been done yet that clinicians ask and providers ask is, okay, if we agree that this is a good thing to do, what are the five to ten questions we should be asking families repeatedly. And that, to me, is the next step.

That said, from a social work perspective, some of the most important questions to ask the person in the family to engage them further in thinking about the rest of their life and the quality of their life are things like what matters most to you? These are open-ended questions not necessarily -- but they're really important for quality of care.

Another important question that we always found at the Family Caregiver Alliance which was so helpful is, what is your greatest worry?

And you get good information from questions like -- what is your greatest worry? What matters most to you? Things like that, but they're not necessarily quantifiable. It opens it up though.

MEMBER GROSSMAN: So, I agree that I think that it's an important question, but it's a very difficult question, in part, because of trying to figure out how to frame it.

For some folks, the concern is a very immediate one. I want to be able to walk better. I don't want to fall as much.

Other folks might be a question that's much larger in scope: I want some pleasurable way to live the next five years of my life.

And what makes it more complicated, I think, is that the frame of the question from the perspective of the caregiver and the patient all depends on what's the antecedent context. So, what's going on beforehand makes it very, very difficult.

Some folks have had, you know, reasonable care. They have a good life plan for their five years, whatever, and they really are concerned about something that's very immediate. Some, you know, small, little concrete thing that's got to get solved and, you know, that's it.

Other folks haven't thought about how I want to live the rest of my life. And it's an educational process.

So, I think that it's a really important issue, but I think that it's a huge issue and very, very complex.

And I think that it may involve thinking about certain -- a question, an open-ended question, the sort that you described might be not unreasonable, but I think that we'd be much more successful getting an answer to the question if we thought about it in different ways, putting it in -- you know, depending on the context.

CO-CHAIR FELDMAN: Mark, and then Mary. And then maybe we'll go get some lunch and ponder. We can talk while we're eating.

MEMBER SNOWDEN: Yeah, I mean, the closest analogy I can come to in what David is talking about in my work is I do a lot of work with problem-solving therapy.

And the fundamental of problem-solving therapy is that it's the patient that gets to decide what problem. I don't do an analysis and tell them, well, these are the problems you need to solve, or I don't train my care managers to do that. And you can then ask how successful was our therapy in doing that.

So, to me, maybe you could measure are you being asked what's important to you, what are your greatest fears, without having to get into us guessing ahead of time what those are going to be.

And then you can ask was your interaction with the health system or whoever, a community-based provider, whoever, was it successful in having you reach the goal you wanted.

And there are actually instruments that have been developed to get to the latter part.

MEMBER BARTON: Well, I just wanted to answer -- to engage a little bit on Murray's question, but I think your example is really perfect in saying that there are pockets of ways that you can do this around all of clinical care.

And usually they've been very siloed and specific, but the -- two things. One is you started to come up with a first step yourself.

So, you said, you know, some of the tools would need to cover short-term goals and events. And there might be other question sets that have to do with, you know, a few years' horizon.

So, you might set up -- so, you might start to gather the criteria that you would use to build something like this just in the way that you started doing.

And then the second thing I would say is that in the, you know, the generic version of this, the goal attainment is measured against the goal that was set by the individual.

So, notwithstanding the fact that they're coming from all different places and they're coming with all different previous contexts, you would be assessing the success of the clinical encounter in helping this patient meet their goal, not someone else's goal.

MEMBER GROSSMAN: Yeah, but that's the kind of thing that lots of docs do when the patient comes into the office. They say, how can I help you today?

It's a very straight forward kind of question and, you know, we ask in an open-ended way -- I ask it in an open-ended way to try and learn what are the significant -- some people come in with a short-term response. Some people have a long-term horizon kind of goal.

But the, you know, even -- so, it's important to put it in the context of the individual. And they come from different perspectives and it's a tough thing to capture.

So, I can ask the right questions, I think, but putting it in the context of that person's previous experiences is, I think, a very difficult kind of thing for somebody to do, a doc to do in an office.

CO-CHAIR FELDMAN: So, one way into this or out of this might be to say that as part of the shared decision-making construct that we have asked for, that we should not only be assessing for personal treatment goals, but -- since this is something that's going to be done repeatedly over time, but also assessing as to whether the, you know, perceptions of whether a person's treatment goals are being met or, you know.

In other words, they're not just asking me, but is it -- does it seem to be making a difference? And that's certainly -- I -- one way into the process.

Joan, and then lunch.

MEMBER TENO: In that case, I'll just remind us that we can't always get what we want, to quote the Rolling Stones.

CO-CHAIR FELDMAN: Great. Grab your lunch. I guess make a quick pit stop if you need to, and then we're going to come back as soon as possible because the idea is a working lunch.

(Whereupon, the proceedings went off the record at 12:31 p.m. and went back on the record at 12:50 p.m.)

CO-CHAIR FELDMAN: Okay, folks. At this point, we're running about 20 minutes later than we thought, but that's because we had such a good discussion and we identified all the problems of the field and we solved at least 15 of them.

(Laughter.)

CO-CHAIR FELDMAN: So, we thought that we would use this last part of our meeting as an opportunity for people to reflect back on the last day-and-a-half. We've had some really probing and sometimes encouraging and sometimes discouraging discussions.

But, to give each person an opportunity here, essentially, to leave us with your, I don't want to say parting word because there will be additional future communications, but with what's the most important thing you want to convey to the rest of the group today as a result of the conversation that we've been having for the last day-and-a-half.

And I mean it's the kind of thing you're going to walk out of this room and, instead of saying I wish I had said that or I wish I had emphasized that, that you actually had an opportunity to do it. And, if you'll recall Eleanor's parting words were, in fact, the importance of identifying low lying fruit. And I think we've had a lot of discussion about that.

If there is something that somebody else has already said that you want to emphasize, I would just urge you. I think that's really important to reinforce it but don't feel obligated to go on and on about it. And why don't we start over here? Yes, Katie.

MEMBER MASLOW: Sorry.

MEMBER STAPLES: That's okay. On the last slide under the Tests and Measures, we talked about safety. And, while safety certainly can be a pre-existing measure of fall safety or environmental, I think really safety could be not all encompassing but maybe all under-encompassing rule under each of the categories we talked about today, in that safety applies to everything that we talked about.

And I just wanted to make sure that we didn't ignore that safety issue for everything from physician making a diagnosis and recommending what happens next to all the other categories that we talked about.

CO-CHAIR FELDMAN: Katie?

MEMBER MASLOW: I was just talking to Bill about this for a couple of minutes and it seems to me that the point he's making is really important.

I know we talked about safety issues but, really, one of the things about a person with dementia and one of the fears that affect family members are safety things. So, the person's inability to judge what a risk is and all sorts of things are very important. And I wonder if we've adequately gotten that into our thinking here.

CO-CHAIR FELDMAN: Is that your departing word or do you want to have a little discussion?

MEMBER MASLOW: That can be my parting word.

CO-CHAIR FELDMAN: I'm game for more discussion if people want. I don't want to herd us into --

MEMBER HASHMI: The only thing I would say is that that's a very important point and I agree that it should be part of the sub-domain or a running theme throughout all of the metrics.

CO-CHAIR FELDMAN: I think one of the things we've pointed out here is that, you know, a lot of times when people think of long-term care, they only of nursing homes. When they think about dementia, they think about memory loss and nothing else.

And, when they think about safety, they think about falls or they think about, you know, maybe wandering. But these are all issues that are multidimensional and have particular implications for people with dementia.

I don't know if we're going to have definitions or something at the beginning of the report. But I think we've got lots of examples of terminology that's often too narrowly applied or words that are too narrowly defined.

MEMBER MASLOW: I think, if you think about what freaks family members out and impart with respect to managing co-existing medical conditions, it is safety in a way. Okay? So, the person doesn't understand, often, what needs to happen in terms of diet, medications, tubes, exercise, anything like that.

And, so, a family member is trying to watch and be sure the person's care is all right. And the same in hospitals. What agitates nurses and aides is there's a person who, they may not know it, but the person is going to fall, wander someplace, not eat, roll over the wrong way, all of those kinds of things. They are medical safety kind of issues.

So, I think maybe, Karen, if you could just see, as you go through, is this there enough and that the safety questions are a problem to family and for the person.

MS. JOHNSON: Yes. So, I think I may need to talk a little bit more offline, maybe, with you, Bill, and make sure that I'm understanding because I think I was coming at this from the idea that we already have several safety measures and I fall into the category, you know, we've got falls, pressure ulcers, that sort of thing.

And, if we, at the very least, do some stratification, that would at least be a start. That may be some low hanging fruit. Sounds like you're talking about going a little further.

MEMBER STAPLES: And even including, you know, abuse for that as well.

MS. JOHNSON: Abuse.

CO-CHAIR FELDMAN: Also, I think this goes to the issue of why does it make a difference to detect someone and to actually record that a person has dementia because there are wide ranging, you know, sort of global safety issues. So, that's less the measure-specific and more the why does this make a difference.

MS. JOHNSON: So, that would be good context. Yes.

CO-CHAIR FELDMAN: Yes. Yael, you have the privilege of being the first person to leave us with your parting thoughts.

MEMBER ZWEIG: So, I guess I was just thinking, you know, what was my take-away and just to kind of fill in any gaps that I thought maybe we didn't address. And, so, I think we've talked a lot about the sort of important interplay between kind of the medical system and all the community organizations.

But what we didn't touch upon much is also just importance of the interplay between interdisciplinary and multi-disciplinary collaboration and collaborative care, especially like sort of just to get back on what Lynn said. You know, clearly, the take-away here is what caregivers really want is the concrete services and the supportive care and referrals.

And, yet, the person who is kind of expert in that area, you know, often the social worker is just not a part of the team, you know, in your typical primary care practice.

And, so, I think kind of my takeaway here is to also think about, you know, the role between medicine and nursing and social work and physical and occupational therapy and all of, you know, the other kind of resources that come into managing, you know, these patients that involve, you know, a lot of services outside of your typical medical diagnosis.

MEMBER BAYLIS: I really enjoyed the process. Particularly, yesterday, when we brain stormed al the ideas and, then, we did the multi-voting. And to just see the degree of agreement that we had was quite interesting. And, then, being able to assimilate and digest all that today and go through it and refine it, I think it was a very good process.

I am proud of the work that we've accomplished and looking forward to the next step. And I've enjoyed getting to know the people in the group. I think that everybody is bright and has great experience and has a great deal to contribute. So, it's been a very good experience. Thank you.

MEMBER CARNAHAN: Yes. I've really appreciated the group's willingness to take on the idea of person-centered care and shared decision making. And I think a lot of those things are going to be crucial to whatever recommendations come out of the group.

But sort of on the flip side of that there may be some things that we think, if good shared decision making is done and good education is done and good clinical care is provided, they're just not going to happen.

So, if we can also maybe think about some quality metrics -- I know this a little late in the game to consider, but -- that are black and white. If there's anything out there that is truly black and white, it can be applied, that people should not get this or they should very rarely get this, if they have dementia.

If good education is done, then it won't happen. And, you know, those are things that are low hanging fruit that could be implemented.

MEMBER TANGALOS: When I think of the performance gap, I still come back to the same issues at hand, that the healthcare team doesn't grab on, doesn't lock onto the patients, don't run toward the diagnosis. They don't rise to the bait. And I think that is a performance gap.

And, so, that gap and the way we deliver those services are what I'd like to see as the outcomes.

MEMBER STAPLES: And I have already talked about my safety issue but I can say I'm much more learned for being here these last couple days with all of you and it's great to see the compassion in you.

MEMBER GROSSMAN: I want to thank everybody. I've learned a lot over the past two days, I lot of things I just didn't know about. And I think it's really a benefit to be able to hear everybody's opinions. And I've just learned so much. So, I want to thank everybody for all that I've learned over the past couple of days.

I suppose that my parting words have to do with the assumptions that we make about what constitutes dementia. And I think we make lots of assumptions about what dementia is and I think that that drives where we're going. And I think that lots of those assumptions -- and when I say assumptions, I mean assumptions in the community -- are not necessarily accurate.

So, I view dementia as a life span issue, something that begins early on in life and there are lots of things that we can do to try to prevent many preventable causes of dementia. And, when we're stuck with the assumption that dementia is something that only occurs in folks who are older, I think that really does a disservice to us, to our community, to our population.

I think that it's not a fair assumption to say that dementia is just a problem of memory. I think that dementia involves any change in any domain of cognition, social behavior, language, interspatial functioning, lots and lots of domains. And I think it's important for us to try to remember, it's important for me to try to remember that dementia isn't just about memory.

It's those kinds of assumptions that I think are important to push. They're all aspirational. There aren't things that we can do lots about now. Although there are some things we can do and I can certainly see a way forward, although it's a 20 year plan. It's not even a five year plan.

But I think that it's important to have those goals. It's important for me to have those goals and maintain those goals and I see that this Committee is a step on the way of trying to attain those goals. And, so, I've really learned a ton over the past two days about this whole process. And, so, I want to thank everybody.

MEMBER FRISS-FEINBERG: I appreciate being part of this Committee. It's been a very thoughtful dialogue and process and two things come to my mind. I'm very please that NQF, and it would especially be true for this group with dementia care as the focus, is looking at not just the medical health side but the social care side as well. And I think for NQF to take the lead on that is critically important.

And, secondly, it was very gratifying for me not to be the only one, usually I am, talking about the family. And, again, not a surprise, because we're talking about dementia care.

But for NQF to recommend some measure of development so that families are no longer invisible, they are recognized, their needs are assessed and they are addressed and supported will be huge. So I thank you.

CO-CHAIR FELDMAN: We caught Joan in the middle of a biteful.

MEMBER TENO: So, I don't have much of a parting word except, you know, maybe we should follow the lead of the New York Times and stop using the words informal versus informal care givers.

MEMBER REUBEN: You know, when we go around the room like this, I always feel like I'm back in AA. And I'm Dave Reuben and

I am a recovering dementia care provider. But, in any event, it was a wonderful experience for me to connect with some old friends, some very old friends, and meet some new people and get their perspectives.

The take-home messages I would give is some of the stuff that we came up with over the past day-and-a-half are going to be very difficult. They're going to be very difficult. They challenge paradigms. NQF and many other organizations work in really a medical framework.

And, in fact, much of what we talked about today is outside of medical framework. It's outside of provider-oriented goals. These are going to be very difficult paradigms. My take-home message to NQF is don't do what's easy. Stretch for the stars and do stuff that's meaningful. You only go around once in life and you should go for the best.

MEMBER BARTON: I think I should

get a prize for having to go after Lynn and Joan and David here. Okay. So, I would say do both, easy and hard. And, in the short-term, I'm just going to punch on things that have been discussed before.

So, immediately short-term win is stratification of important measures. And you've heard a good list here today of what would be cool ones to start with. And, then, Joan didn't take the bully pulpit to repeat her own point. I'm going to repeat it: proxy respondents for survey measures that are already in use. I'm banging the table.

Not short-term but, in the intermediate, I'll just remind the group about what I said before about case finding for dementia could potentially build on a risk profile tool and this would be something that the Committee could recommend further research on. Just validation of an existing tool, for example, has been recently reported.

And, then, the two things that I would be so regretful if the Committee did not emphasize in the report, one is to get a little bit ahead of the terrible silos that our healthcare system is stuck in and find a way for those shining examples of either states that have the demos or dual plans or other places, pace programs, other places where you could create a measure that other people would not even be able to dream of yet that had something to do with transitions of care and the provision of appropriate information from one stage to the next and the examination of whether the useful information made it, not just did you give the patient one.

But, you know, moving towards outcomes. I think that would be a good way to start because those are place that could use the measures and it would be a way to inspire the rest of the system to become a system that could also report measures like that.

And, then, the second thing to reach for is in the goal creation and attainment, which requires that you talk to people in an open-ended way at first and, then, potentially, in a more standardized way about what are the things that they care about. And, then, you follow up on it and ask them again.

MEMBER SNOWDEN: Yes. I think I would like to focus my comments on sort of the next steps with sort of the example of how we started. And, if I sort of summed it up into sort of two main products, there was a conceptual model.

And the conceptual model had the advantage of being comprehensive. And we spent a lot of time. I'm actually not a big conceptual model person but I was impressed with how, with each iteration, it actually did get better.

My concern about what we've done

over the last day-and-a-half is that we have very quickly gone from a very big list to a very short list. And part of me thinks that the future work will be to figure out a way to iteratively think about what we did and not prematurely close the door to ideas that may, simply for the lack of time, not have the same amount of discussion.

To me, that's going to be the real challenge, to have the written part that goes over the prioritization really do justice to the breadth of what we did, while also trying to get to a smaller set of things that are very well explained.

So, to me, the bullet points I think I sort of get. But just like the model benefit, I think they're going to need to be iteratively edited as well.

MEMBER HASHMI: So, for me like Mark said, the whole experience of going through this measure-development construct was a new one and I have really loved the process of sort of coming at it from a larger construct and, then, working towards measures.

The worries that I have is that, you know, you're developing this work in the environment of such rapid change in the external environment. And to not forget that dollars really do drive behavior, intended and unintended.

And the payment model, the provider payment model is undergoing rapid innovation and there is also kinds of, even now, emerging intended and unintended behaviors on the providers' side.

There's rapid assimilation of a variety of practices being sold, for example. So, there's a lot of change going on and we don't yet know what all it is going to mean.

So, to keep that in mind, that, you know, if you want to put something out there that considers what's happening in the external environment.

Then, the last thing is just an observation. You know, when we talk about team-based care in medical homes and ACOs, geriatric care is the ultimate example of team-based care because this team extends not only in the healthcare setting but it is a team consisting of providers in a healthcare setting and others both those that are recognized, you know, and unpaid providers of care.

So, this is the ultimate team. So, how do we evaluate the effectiveness of team-based care in this larger team constant?

CO-CHAIR FELDMAN: Susan, I feel that I should have started with you. We've so poorly neglected you. Are you there?

MEMBER COOLEY: I'm here. I don't feel neglected at all.

CO-CHAIR FELDMAN: Good. Okay. So, now is your time to leave us with your parting thoughts. You have the floor.

MEMBER COOLEY: Well, it's never

over. I'm sorry but, you know. I feel like I've been well included and I thank you all very much. My regret is that, by not being able to see you visually, I don't know who was speaking. Some people's voices I know but even people I know very well sometimes I can't remember their voices. But many people's voices I don't know. So, I don't know who said what.

So many things I agreed with and it's like, yes, yes, yes. I just feel like you didn't see me nodding my head and clapping and do other visual responses. But one thing I do want to say is that it has been very helpful to me to listen to as well as participate with this broad group.

I've been dealing with these issues or trying to grapple with then anyway for some time. And, at least, there is some validation that it's not just me not being able to solve all these problems. But, you know, there are no easy answers.

These are many, many needs, of which I knew, some new things that I heard at this meeting. There are very complicated measurement issues and it's just not an easy area. So, just like everybody else, I have my favorites of what I think are top priorities or ones that are more urgent needs that others flow from. Others have their favorite lists.

But the conceptual model to me also we very helpful going through that experience as a overarching guide. So, I appreciated having the conceptual model as something to go back to, after we were deconstructed, as I would have said, over the past couple of days.

And, then, I will just also say that many times I feel I am overwhelmed by this because there are so many needs, such pressing issues and it can feel overwhelming. I know I feel overwhelmed many times. And one of my bosses, in a different but related context, told me don't lose heart. So, I wrote that down. I have that in front of me among other things on my computer. Don't lose heart because I do believe, at least I hope, that we can make progress and we can help improve lives. We can help people and that's a bottom line.

So, I'm trying not to lose heart and I've found a lot of encouragement through the rest of you at this meeting.

CO-CHAIR FELDMAN: Thank you, Susan. Matthew, you haven't --

MEMBER JANICKI: I'm dealing with a flight cancellation, so my mind is trying to get home. Could I pass for a minute?

CO-CHAIR FELDMAN: Sophie, do you want to?

MS. OKOLO: I just want to say thank you for all your comments and ideas. I have really learned a lot the past two days. And, normally, one thing will be I think, until we become a pro-aging society, then these things can be works in the well. So, that's my only think. Thank you.

CO-CHAIR FELDMAN: So, I guess it's my turn to say a few words. There are two words that my friends and colleagues would never use to describe me. One is humble and the other is quiet.

So, I must say that I really feel great humility at being in this group. You know, the amount of knowledge, expertise, wisdom and commitment to this whole area is just so great. I've really been humbled and I really thank you.

You've contributed enormously to this meeting but, also, I really, as I think I said at the beginning, have been, you know, genuinely impressed at people's willingness to do extra tasks and to do things by email and so forth. That's not always, by any means, typical of a group like this. And, so, that's number one.

I also wanted to thank my co-chair, Eleanor, from whom I've also learned a huge amount and who was just amazing. And to thank the staff, Karen and Juliet and Taylor. You get a sense of all the lot of preparation that they've done for this. And, if you could have seen. The annotated agenda is about ten pages long and there is just not a detail left.

And I think, certainly for myself and I probably speak for Eleanor, you know, part of the reason that this meeting has gone so well has to do with the amount of care and preparation on the part of the staff that went into this. So, I'm really grateful for that.

I do have a couple of parting shots. One is kind of this lingering concern. There's a lot of research on care coordination and care management and there's, you know, in one of the early IOM reports that said, you know, if everybody's accountable, nobody's accountable and that the person, they used the term "patient," but if the person and the family don't have sort of a person and a phone number who is the single accountable person, that this doesn't work very well.

And, so, I deeply believe and we have taken the approach about recommending performance measures at all levels and across the system. I'm not sure that we've fully addressed this issue of when a person encounters the health and social service system, is there an accountable person. I don't know how we do that.

But I mean we talked a lot about linkages and stuff but that's something that's kind of lingering in my mind. Secondly and granted I do speak from the point of view of somebody who's sat in a large and sophisticated community based healthcare organization over the last almost 20 years and, also, as a lay person in terms of my own experience, but I want to be cautious that, in this report, that, in our effort to include community-based organizations and families, that we not absolve the medical part of the system from its responsibilities here.

And it goes back to what, you know, Eric had to say. It's very easy when the person and the family are in denial and it takes a lot of time and it's very complex to just treat the immediate, whatever the immediate thing is not to delve further. And, so, I think we've been very conscientious and genuine in talking about the role of the community-based organizations and so forth.

But, in doing so, I want to be sure that we don't absolve the medical part of the system here from its responsibilities and recognize that very often families who are in denial, even when they contact the Alzheimer's Association, they're looking for a physician.

And, you know, most often people are going to their primary care physician with these amorphous unnamed things that are bothering them and they're looking to their primary care physician for some advice and recommendation. And, so, again, I think it's very important that we emphasize the role of the person's point of contact with the healthcare system.

So, you see, I said I was feeling humble but I definitely was not quiet. You know? So, thank you all. Karen, you wanted to speak and do we do our public comments next? How do we want to do that?

MS. FELDMAN: Hi, operator. Kathy, can you please open up the lines for public comment?

OPERATOR: At this time, if you have a public comment, please press star one on your telephone keypad. We'll pause just a moment to compile the roster.

MS. FELDMAN: We'd also like to

invite any of the public attendees to offer comment at this time.

OPERATOR: Again, for comments, please press star one.

MS. JOHNSON: I'm going to give D.E.B. a chance. We've heard from her a couple of times. So, just in case you want to have some parting words.

MS. POTTER: I just wanted to thank you all for your thoughts. It's really appreciated. As someone who comes from long-term care, it's really nice to hear long-term care and healthcare be talked about at the same meeting and community-based supports and social services.

I want to thank you all for your aspirational thinking because, in order to move the system, we have to be aspirational. That's my personal opinion. Do not attribute it to any organization I work with.

(Laughter)

But I just wanted to thank you and

I wanted to thank Penny and Eleanor and the NQF staff for all their help. And you should all give yourself and everyone else an applause, including Susan. So, thank you.

(Applause)

MS. JOHNSON: Okay. We're going to end up with just a few final next steps. Since everybody else got to say thank you for everything, I'd really appreciate, I know you guys have given us a lot of feedback, a lot of help. My co-chairs have been fantastic. I haven't had nightmares about the meeting because I knew we'd be in good hands.

And D.E.B. is a great GTL. You wouldn't imagine the number of emails with information that she sends me. Almost daily I get something from D.E.B. and I really appreciate it.

MS. POTTER: Please, not daily.

MS. JOHNSON: Well, maybe it just seems like daily sometimes because I can't keep up with everything. But I've learned a lot from you and I really appreciate that. So, it's just great to work with people who care and are willing to share with others.

So, with that, let's talk about next steps and what we plan to do next.

MS. FELDMAN: So, obviously, after this meeting, we are going to be synthesizing all of these deliberations. We'll be drafting a meeting summary over the next week, which is due to HHS within seven business days. So, that'll be our first task at hand. We'll be sure to circulate that to the group.

And, then, after that, we are going to get into drafting the report. And we'll be sure to involve you and we'll be following up. We've identified at least two subgroups of the Committee that we'll be working with during the next summer months. And, just as this slide indicates, the draft report is due to HHS on August 15th.

There will be a public comment

period on that draft report. It's a three-week public comment period between late August and early September. There will also be a public webinar. But the final report due to HHS on October 15th.

MS. JOHNSON: And let me close with just a couple of things. We've mentioned at least twice I think in these meetings and even before that that there are the other task five gaps projects that are going on. The ones that are particularly salient to us are the workforce one, the care coordination one and the person and family centered care and outcomes task.

And those reports, they had meetings similar to this. Those reports are going out soon for comment. Several of you, throughout the meeting, have made comments that make me think you might be particularly interested in one or two of those. So, if you have the time and the inclination, it would great if you would take a peek at those.

And, if you have any comments, particularly if you have it in terms of, you know, how the dementia might be folded in, so, again, we're learning from them and we did that specifically for this project. But, if you have any comments for them about how workforce and dementia should go in, so that they can enfold that into their work, that would be a nice feedback loop.

So, we're not going to ask you formally to do that and certainly not as a group to do that. But, if any of you personally have the inclination, that would be great.

MS. FELDMAN: And I can circulate the link for that.

MS. JOHNSON: Well, we have an half hour extra time. I don't see anybody sad about that. So, safe travels everyone.

(Whereupon, the above-entitled matter was concluded at 1:27 p.m.)

CERTIFICATE

This is to certify that the foregoing transcript

In the matter of: Alzheimer's Disease and
Related Dementias Committee

Before: NQF

Date: 06-03-14

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