NATIONAL QUALITY FORUM

Moderator: Juliet Feldman
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Operator: Good morning and welcome everyone. For technical support with the web portion of today's program, please send an e-mail to nqf@commpartners.com. You can also use the chat box area to send us a message.

Today's meeting will last up to two hours and include specific question and answer period. You may submit a question at any time. To do so, simply type your question in the chat box on the lower left corner of your screen.

We'd like to draw your attention to the links area located to the left of the slide. The links menu contains the links – a link to project web page as well as a link to the presentation slides. Clicking on any link will open them in a separate web browser window and will not disrupt your viewing of today's presentation.

Following today's meeting, you'll be able to find a copy of this presentation on the NQF website with full audio included.

And now it is my pleasure to hand it over to Juliet Feldman. Juliet, please go ahead.

Juliet Feldman: Hi, everyone. Welcome. Welcome to the webinar today and we are so – so thankful that you are here and made the time. And we are very excited to be gathering your feedback over the next hour or two.

So on slide two, we present what we're hoping to achieve during today's webinar. We sent a bunch of materials to you in advance of the call. And as you saw, we have – we have a lot to – we have lot we want to get through. So what we're hoping to – to discuss with you all today is give you an overview of the project and discuss the project objectives in the timeline.

Discuss important considerations for the conceptual measurement framework that we'll be developing as part of this project. The environmental scan of measures and measure concepts as well as literature review. We'll also be gathering early input on the potential approaches for prioritizing the measurement gaps as well as discussing next steps for the project. So a lot to get through.

At this point, I'd like to just have everyone introduce themselves. We have the list of the advisers for this project on the – on the slide here. And so if we can go around and just quickly introduce yourselves, that'd be wonderful.

Cyndy Cordell: Sure, this is Cyndy Cordell from Alzheimer's Association. I am the Director of Healthcare Professional Services.

Juliet Feldman: Hi, Cyndy.

Penny Feldman: Hello?

Penny Feldman: This is Penny, who do you want to go next?

Juliet Feldman: Sure, Penny, go ahead. Thank you.

Penny Feldman: This is Penny Feldman. I'm the Senior Vice President for Research and Evaluation at the Visiting Nurse Service of New York and I am preside over a research portfolio that's focused on improving quality of care through strong measures and underlying research to improve evidence-based practice.

Juliet Feldman: Katie.

Katie Maslow: And this is Katie Maslow. I'm at the Institute of Medicine in DC. I'm a Scholar-in-Residence there.

Juliet Feldman: Thank you.

Mark Snowden: I'm Mark Snowden, Associate Professor in Psychiatry of the University of Washington.

Juliet Feldman: Is David Reuben on the line?

David Reuben: Yes, I am. So I'm David Reuben. I'm a geriatrician in UCLA and I lead the UCLA Alzheimer's and Dementia Care Program which a CMMI innovation channel challenge org.

Juliet Feldman: And Joan.

Joan Teno: Yes, hi. I'm Joan Teno. I'm a hospice physician and geriatrician at Brown University in Health Services researcher a lot of work on looking at quality of care for people with end stage dementia.

Juliet Feldman: Great. Thank you, thank you all. We'll just go around so you know who's here at NQF. My name is Juliet Feldman. I'm the project manager for this project. And excited to be here.

Karen Johnson: This is Karen Johnson I'm the Senior Director on the project. So I'm just kind of here to help, to guide, and help inaudible about the subject matter content along with you guys.

Taylor Myers: Taylor Myers, Administrative Assistant. I will be supporting this team and looking forward to it.

Gail Hunt: Sorry, this is Gail Hunt. I just – I'm the head of the National Alliance of Caregiving and also on the Board of the PCORI, Patient-Centered Outcomes Research Institute.

Juliet Feldman: I'm glad you can join us, Gail, and welcome.

Gail Hunt: Thank you.

Deb Potter: This is Deb Potter from the Agency for Healthcare Research and Quality and from the Office of Secretary. I am the HHS subject matter lead for this project, and I also lead a group of over 25 stakeholders from HHS who are following this project.

I'd like to take this opportunity to thank all of you who are participating. We are very grateful for your time and expertise.

Jane Tilly: And this is Jane Tilly. I'm with the Administration on Aging which is part of the Administration for Community Living and I work on the dementia programming there.

Juliet Feldman: So that's our team. Wendy, can I pass it off to you to introduce yourself and give some background on the larger Prioritizing Measures project..

Cille Kennedy: Hi, this is Cille. Can I interrupt just so that people know that I'm here? This is…

Juliet Feldman: Sorry, Cille.

Cille: Quite all right. I'm at ASPE and I'm the government task leader for this particular project and I am extremely grateful then to pass on – Deb did nicely, to pass on to Deb my heartfelt gratitude in her role plus everybody else.

Wendy Prins: Thanks, Cille. Hi, everyone. This is Wendy Prins. I'm a Senior Director at NQF as well. And I'm sort of providing broader oversight over this task. There are several different components underneath, which I'll talk about in a moment. But it's wonderful to be here.

Just some broader sort of framing comments about this project and sort of where it sits into the bigger picture of things, NQF as you know has been endorsing measures for – probably going on 12 or 13 years now. And one of the things that frequently happens during our endorsement work and other works such an MAP and the National Priorities Partnership is, we're frequently identifying gaps in measurement in important areas.

But until the Affordable Care Act, there wasn't really a dedicated sort of funding source for the identification of measure gaps. And so, the legislation basically wrote in to convene the consensus-based entity which is essentially NQF to do some more concerted work in this area. Identifying gaps, and really looking at where, we should be focusing our efforts and funding to develop measures that will really matter. So that's one of the things that we, that we certainly sort of say about this project is we're really looking at measures that are matter – that matter, and will really help to – to drive improvement in these various areas.

So the next slide is, basically our go-to depiction of the national quality strategy and the three aims and the six national priorities they're in. And this is sort of our guiding light and as you all go through your work, what we would ask you is to also keep these in mind, that really we want to make sure that we're improving care but also improving health and reducing cost. So that – that triple or the three-legged stool, you know, we can certainly, probably, pour a lot of money into things that – that may improve being marginally but, you know, is it really helping us to sort of move this entire thing forward.

Also included, to six priorities within that and I think it's pretty clear how this – this patient population in particular, really hits on a lot of these areas. So I want to noodle on this, but just please keep those in mind as you move forward.

The other projects that – that we have going for similar work that you'll be doing are up on the screen. So we have five concurrent projects going. And I'll sort of call your attention to ones that follow Alzheimer's disease, care coordination, health workforce, and person-centered caring outcomes. And as you can imagine and as you will – I'm sure discussed today, there is a lot of interrelatedness between this project and those. And so, when Juliet goes over the timeline, she may mention that this project is actually following a little bit of a delayed timeline than the other ones. And that's to allow the work of those groups to feed into this one.

So where you, you know, really start honing in on person-centered care and outcomes or in care coordination or perhaps even issues with the workforce to care for this patient population and their caregivers, we may find opportunities to sort of connect the – and bridge the two groups.

So we may find some things, they may bring some things to us for you to consider, but we're really – although these are five separate committees, because of the interrelationships, we're really working at NQF to make sure that we connect the dots for you and to make sure that we're not being duplicative but taking advantage of the cross work.

That's all I have. We're really excited about this work. I think we've heard from a lot of folks that it's so important that we start these discussions and get this prioritization up front so that, you know, the resources that go into measure development which is very time-consuming, very expensive is focused on efforts that really, really matter. And so I'll just echo everyone else in thanking you for being here and I'll pass it back to Juliet.

Juliet Feldman: Thank you, Wendy.

So I'm going to give a very brief, just overview of what our goals are for this project. We want to get to the meat of the discussion today. So I'm going to breeze through these next couple slides. So on slide nine, it outlines the project objectives and purpose and what we're trying to do, or what we're going to do is provide HHS with recommendation on priorities for performance measurement related to the Alzheimer's disease and dementia population.

So in summary, we're going to be working with this committee over the next several months to identify what performance measurement efforts should head to get the most sense of the buck.

Next slide.

So these next couple of slides just outlined the key project activities. We are in the midst of convening a multi-stakeholder committee to inform – to inform this project. And today is our Advisory Group web meeting where we convened eight advisors who will we providing preliminary input on the project as the full committee is being seated.

So the – one of first major tasks of this project will be identifying and/or modifying a conceptual measurement framework. NQF will be conducting an environmental scan and will propose relevant conceptual framework. The identified framework will offer measurement domains and sub-domains that align with the triple aim. And we will be seeking ongoing feedback from the committee throughout this entire process.

Then using this framework, we will be conducting a measure gap analysis. We will be doing an environmental scan of evidence, measures, and measure concepts that map to the domains and sub domains identified in the framework. The committee will consider high priority opportunities for measurement development and endorsement and we will be considering the possibility of these identified measures and measure concepts.

And then lastly we will be convening via an in-person meeting in the spring for the committee to basically prioritize – prioritize opportunities for measure development and essentially make recommendations for where HHS should focus their performance measurement efforts related to this population moving forward.

Deb or Karen, do you have anything to add to the project overview or…

Deb Potter: This is Deb Potter. I just wanted to make it clear especially for the public that's on the line that the Advisory Panel members that we're listening to today are a subset of this larger multi-stakeholder panel. So when Juliet refers to the committee, it includes the Advisory Panel as well as the broader group.

Juliet Feldman: Thank you, Deb. I – if there are no questions from our advisors, we'll move forward with the discussion.

Karen Johnson: OK, this is Karen from NQF. So first, I'm going to apologize in a way because most of you, I think, the advisory committee members can only stay on with us for an hour today. So we are going to try to pack in a lot of stuff and I realize that there is no way we're going to get to all the sessions and all the things set. Hopefully, you had a chance to read the memo that we sent out that gives some background on what we're trying to do and how we're thinking about going forward.

So one of the main things to make sure that everybody understands and with Katie and Gail, you guys know this very well. But we're really basing our work of the work that's already been done first from the May 2011 conference and then a follow-up one-day conference in December of 2012. And so a lot of foundational work has already been done. So a lot of what we're trying to figure out especially early on is how can we best build on that foundation, what else do we need to do to kind of complete that side of the work and then move us forward.

So that's kind of what this hour is about. So let me go on and also I do want to say thank you very much to the AD-MI folks who provided their draft manuscripts for us. So hopefully, you guys have had the chance to look at those – very helpful and, you know, some of the background of what happened in those meetings is in those manuscripts. So thank you for allowing us to see those.

So I want to go straight into the Conceptual Model. So basically, we have a straw-man Conceptual Model that we wanted to draw your attention to. And pretty much we came up with this from two sources. One was a model what was presented in the May 2011 conference and then the other one that was done as part of the AD-MI project. And we've kind of tried to merge the two. And basically, there's a lot of questions on here so we don't expect that this is the final model by any means that we thought it'd be easier to give you something to react to.

So I think my first question is what are your initial impressions of this draft model knowing that we can't probably get into a weeds that maybe if we can take just a few minutes and talk about the model. And then also, this – the way it's kind of presented here is based on an NQF Episode of Care Framework for measure development, but, you know, we call it here the bubble diagram. But there has been other frameworks proposed including Multiple Chronic Conditions Framework and that is a reference we – in the appendix of the memo that we sent out.

So one option is to not have this draft and go with something more like the MCC Framework, again, noted in your appendix. So that's something that we can talk about. I think another kind of main question is given the state of the evidence for treatments and prevention and diagnosis and straining in all these good things is this model as it is too much of a medical model then we need to kind of back away from this. So with that, I think maybe we can just take a few minutes for committee members to give us some first impressions.

Penny Feldman: Well, this is Penny. I'll plunge in since you raised it. I actually, you know, I looked at the model before I looked at the others and I liked the model. But I – the big question that did occur in my mind was really how are you defining care management and treatment, because I do in my mind have a very broad version of that and involves coordination and the non-medical part of management and – of management certainly which – because so much of the management really happens at home and outside is the medical setting.

So, I guess, my question was really, what did you have in mind when you were defining management – care management and treatment? Because I – it's conceivably one could have a very broad definition of it and it really depends how you flash out the model and, you know, and the measures.

So that was a question in my mind, sort of what is your mandate and does it go beyond the medical, which I would hope it would in the case of this population.

Karen Johnson: So this is Karen, and we were thinking of a very broad way of thinking about management. So we try to share that a little bit with maybe – if we continue with this kind of bubble diagram, you know, do we need to have different trajectories or something like that because so much care is informal. You know, there is pharmaceutical management versus non-pharmaceutical. So we're opened to any kind of way to pictorially illustrate that kind of stuff in how ever way that you guys think makes the most sense.

Joan Teno: Hi, Joan Teno, I'd like to just maybe to – first of all, since this is a fascinating way of presenting this information, I guess, one thing is if there's some warnings that it can show how the patient trajectory varies with time, thereby adding sort of another element to this, and also showing kind of a caregiver trajectory varies of time to emphasize the certain role that caregivers have in focusing on providing what appear to this population. And I just – two other things I'd like to throw out is should be at all reflect some of the settings of care that these people are in noting that most likely when people get the severe stage three, they're in an institutional setting. And should we call it End of Life or can we somehow try to really endorse a notion of person-centered care and the need for advance care planning.

Gail Hunt: Empower you to this care.

Joan Teno: Yes, empower the care, absolutely, because I think one of the misnomers is that while using End of Life, we're going to think hospice and type of care are only for people who are actively dying.

Gail Hunt: Yes, so I think if you talk about advance care planning and you can maybe make that clear. But – this is Gail Hunt. I agree, of course, 100 percent with the issue of having to have somehow the trajectory of what the caregiver does because that ties together in some ways the both the medical and the non-medical, with transportation, for example, can be overseeing adherence plus other kinds of activities for the patient with Alzheimer's.

And I thought that in the AD-MI model, the idea of having sort of a formal care, medical care and then informal care was maybe a way of doing that – those big bubbles, you know, those purple bubbles in the middle that we could have. So something is like the trajectory that we'd follow for informal care as we move from mild to moderate to severe and then what is trajectory of medical care. So maybe adding something to this purple bubble.

David Reuben: Hi, this is Dave Reuben. I had a couple of comments here. First I think the Conceptual Model is terrific. One thing that isn't is it's very population-based, et cetera, but it's not patient-centric at all. So this is really a very much a medical public health model of dementia, but it doesn't really have necessarily what's important to patients at least it’s not at the epicenter, whereas the Chronic and the – Multiple Chronic Conditions is at the center. So if there is some way to bring that and then highlight it more in this schema, I think it would be very valuable.

Mark Snowden: Mark Snowden here. My concern about the model is that trajectory seems a really broad term. And I guess I would to like to have it be more specific in terms of bubble about specific outcome.

Karen Johnson: That's great.

Mark Snowden: I'm a little concerned that it is pretty broad so that was getting all inclusive with the earlier comments around having at least something that can deliver on treatment and cost-effective which I think will make it challenging and so my initial inclination is that it probably will need to a bit more narrow in scope to really do that. But my bigger concern is that the trajectory probably need to speak more to specific types of outcomes.

Karen Johnson: And Mark, this is Karen. Thank you for that. One of the questions that we should ask you guys very early on was what kind of outcomes should we be considering here.

Katie Maslow: This is Katie. I was involved in the AD-MI as you know, and so one of the things about the care management and treatment is that we certainly consider that it included the medical and non-medical and any caregiver-related measures we put in there. So we thought of it very broadly.

One thing that is here just in tiny letters under the green bubble is initial detection. My perception is that that needs its own bubble. I think that initial detection is extremely important and that it's not the – it's not the diagnostic process if how will this – how – the identification of cases. So it's controversial obviously and raises issues about screening but it's very important. So I would like to see another bubble there.

Jane Tilly: This is Jane Tilly. I'm going to second what Katie said because a lot – as I read through a lot of the materials, it seems like they focused on people – the measures that are existing now, focus on people once they have a diagnosis, and given rough estimates that half the people with Alzheimer's don't have a diagnosis. The detection is important.

And also – I don't know where this will get reflected in there – in there but not every – I think we all know not everybody who has dementia has Alzheimer's. So some kind of differential diagnosis but what type of dementia people actually have does a have a lot of implication for care management.

So I don't know how that gets reflected in here.

Gail Hunt: And this is Gail Hunt. I would also like to say the initial comments about having a specific bubble that deals with initial diagnoses. One thing that I think is really important is, you know, usually the family knows – begins to recognize that there is an issue, that there are – there's the potential of someone having Alzheimer's or other dementia up to two years before the person gets the official diagnosis. So in some ways if there were a way to sort of shine a light on that are like on that point that two years or one year, whatever it is. When the – when people including the person, including the patient begin to recognize that there's an issue that they need to address, that's the time that, I think, we could also – it would be valuable to clarify that. And that's before the what we call the real diagnosis.

Mark Snowden: Yes. And to me – Mark Snowden here again. I think that would actually start to correlate a program that I would consider one of the first outcomes today is the actual recognition of the process by both provider, the patient and family.

Penny Feldman: Yes. This is Penny. I mean I – I think a lot of these suggestions are really great. And it's always really hard to play with the model but, you know, you might even under the bubble evaluation and initial management called something like early detection relation and staging or something and leave the management for later. But going back to this question about person-centered goals both for the person with Alzheimer's or related dementia and for the caregiver, you know, perhaps instead of those things about comorbidities and safety and End of Life, you make whatever we're going to call it, palliative care and End of Life either another bubble under care management and treatment or its own bubble, you put advance care planning. I would argue as soon as the diagnosis made because planning at the end is way too late.

And then – and, you know, there's all kinds of planning not just about the very end but about the full trajectory. And then maybe somehow bring that circle of the patient or the person and the caregiver, the person with dementia or related cognitive dementia and the – and the caregiver down in the circle underneath where you've got the comorbidities and safety now. And then somehow, the outcome's either encircling them being, you know, quality of life, symptom management, et cetera, et cetera, but really somehow combine your bubbles with that, you know, very compelling chronic condition circles that really does have the person and the – and the – and the informal caregiver right there in the center. But I – it seems to me that that's really important to signal the person's centeredness and then the outcomes can sort of stem from that, recognizing that they would be different at different stages and in different settings.

I don't know how you deal with this setting issue. It's so complicated, you know. I've read them. The move is to have uniform measures but different settings are responsible for different things and so it's really – it's a huge challenge.

David Reuben: Yes. This is Dave Reuben. I absolutely agree with everything you just said and perhaps one way of thinking about it in terms of this model just as you have the comorbidities stretching across the entire bottom there, I think as soon as there is a diagnosis that there needs to be goal-setting. And that goal-setting really extends through the duration of the disease and it has to be accommodate obviously, family and patient preferences and has to also be dynamic. And, in fact, once you've done goal-setting, that can span across settings, across situations, but it has to be re-accessed, some of the – might have goals for early stage dementia. When those complications occur those goals may change. If hospitalized, they may change again or transferred to a nursing home, they change again. Those have to be continuously reevaluated.

Cyndy Cordell: And this is Cyndy from the Alzheimer's Association, and I totally agree that we need a bubble for that initial detection because we know a lot of people don't go on and get fully evaluated and diagnosed. And I also agree with that continuum that it's going to be fluid with your goal-setting.

And the last thing I'll just say is that circle on comorbidities where you put any but especially depression and delirium. I think there's other really important comorbidities in this population, diabetes, CHF, you know, can't be ignored because of the inability for them to manage their disease just because of their cognitive inability.

Penny Feldman: And this is Penny again. I wanted to throw something else that occurred to me as I was reading this and I don't know if it's just more silos or whatever. But for many – for many people especially as Alzheimer's or dementia becomes more severe, there's not only a caregiver, an unpaid caregiver but there's a some sort of a direct care worker or an aid who maybe from an organization and maybe from the grey market. But it's a woefully – woefully under-attended field. And there is so much direct formal care being given by so-called paraprofessionals. And – so one thing that I kept thinking about is – and I'm sure there are no measures out there but that doesn't mean we might not been want to flag the area for improvement.

One of the things that really, really have struck me in my experience is that, you know, there's – there are professionals of all kinds, the clinicians and the diagnosticians in medicine, nursing, pharmacy, et cetera. And then there are the paraprofessionals particularly as the stages get more difficult. And the measures and the training has to be different for them and maybe at the beginning, we just think about the development of process measures. But this was the one thing that wasn't called out in the model. I don't know if it's appropriate to call out the model. But I do see it has a huge gap – not even primarily with regard to measures now but even attention to the training of this population. Just a thought.

Katie Maslow: This is Katie. I have an idea about initial detection and then Gail's point that she raised earlier about the family awareness. So in the AD-MI model, those were two different bubbles. And I think that the right way to do it might be to add a bubble that both of those and to change – to me that's a – something getting towards David's idea of the person centeredness. That the wording – we should try to change the wording of what these different bubbles are to make it clear that we're not talking without just the role wants of the caregiver, the professional or paraprofessional caregiver, but we're talking about this whole area.

So in the purple bubble, the whole area of ongoing care and care management which would include all of the providers as well the family and the person. But we could start that, I think, with this – with a new bubble about initial detection that was written in a way to say that it's often the family that's doing and the person, and then change our wording for these bubbles. Keep the same topics but that they make it more clear that you're talking about everyone and a person-centered focus.

Karen Johnson: OK, I hate to interrupt this because we're getting some really good feedback here, but we have very few minutes left and some more slide to cover. And we're going to play around with this and we'll figure out some way to kind of maybe give you, you know, version 1.1, 1.2 this kind of test, some kind of continual feedback so that we can kind of keep this going.

I think the one question that I'd like you to think about as we do this is a measurement framework. So, you know, how much or at what extent should this model show where we're ripe for measurement. So there's still little evidence on things like screening and that sort of thing. So how do we depict that or duly depict that in this model. And to be honest, that's one reason why I hadn't made a extra bubble for the initial detection even though I totally understand that that's extremely important. So that's some of the questions that I have. So let me go on and again, we'll figure out how we can keep getting feedback from you guys

Penny Feldman: Can I just have one quick thing.

Karen Johnson: Sure.

Penny Feldman: I'm assuming this model stops when patient dies. But I'm wondering if there should be part of the model that goes on and try to capture the bereavement outcomes of the caregiver and I'll just stop it at that.

Karen Johnson: Yes, that's a good point, yes. And I think it should. And you know what, I thought at one point, I had my End of Life bubble going further out but I guess I didn’t quite make that so.

We are internally doing some literature review, just the very basic one. And really it's more just to get us on – to understand some of the knowledge that’s out there, you know, certainly nothing quite, you know, real systematic review of anything. But we – we may get some guidance from you and from the community as a whole on places that we need to continue looking.

So we admit that we haven't really even started taking a peek the caregiver side of things. We've mostly looked that the patient side. And so we have some stretched out five major groupings, prevention, screening, diagnosis, symptom and psychiatric management and treatment as major areas in addition to all the stuff with caregiver.

So I'm not going to ask you to actually answer that right now but I would like you to be thinking about what other things that we need to do a deeper dive into the literature. If we do or if you think that, you know, your expertise will help us and we don't really need to spend time on that. So, we’re really trying to figure out what we'll need to do and how you guys can help us.

So I'm going to put that on the table but not give you time to answer that. And the only reason I want to do that is to go on to the environmental scan which is part of the deliverable for this project. So the AD-MI project that's already done, a phenomenal environmental scan and Katie and Gail can certainly – correct me if I’m wrong on this but I think I feel like that they pretty much were able to find most the measures that were dementia specific for the U.S. And they were able to find quite a few what they call illustrative examples as non-U.S. measures.

So our question to you is how do we build on what they have already done? And then how do we get the committee members and you guys to help us with that effort? So, we'll spend a few minutes on that very large question and I understand that's a huge question, I think.

Gail or Katie, do you want to start us off at all, or?

Katie Maslow: This is Katie. I think that it's pretty safe and as soon as I said that, it will turn out to be not true but pretty safe to say that the measures and in publicly available measures in that U.S. is complete as of last summer. So new measures could be available. I think that there are probably interesting measures that are in the big health plans possibly or maybe some states have measures that we didn't get and that are hard to find. But in the U.S., I would say in terms of dementia measures, that's – they're pretty comprehensive. It's not comprehensive in terms of dementia measures in other countries.

And as – I think that there's a huge – there are a huge number of measures in other countries, but the searching for them maybe we should think of as defining goals or outcome areas or whatever you want to call it, and then looking for measures as opposed to trying to find everything that's there. I think that there's a lot there, British measures, Australian measures, German, Netherlands, and Canadian, and probably many that I don't know about.

Cyndy Cordell: Hi, this is Cyndy Cordell. And I was in AD-MI as well and I agree with Katie. We did a lot of work in the U.S. And, you know, one area focus might be to just look the European countries that have Alzheimer's plan because typically if there's a plan, there are some measures. And, you know, that's something to think about and, you know, and at least hitting and I think there's 18 countries now that actually have official country Alzheimer's plan.

Karen Johnson: Great, anybody else have any advice?

David Reuben: Yes. Dave Reuben …

Mark Snowden: Regarding with main and reporting outcomes and then looking at the measures within those.

Female: OK, right

David Reuben: This is a Dave Reuben. My actual conceptualization of dementia is actually it's not just a disease of the patient, it's really disease of the patient, the family, that unit. And I think that certain aspects of caregiving – caregiving preparation, confidence in being able to care for patients, their loved ones, and stress burden on the caregivers, all would be considered as measures. And that this model – this part doesn't conclude that as much. I don't think indirectly asking caregivers.

Katie Maslow: This is Katie. For the AD-MI measures scan, we found no measures in the U.S. reported by caregivers, specifically about Alzheimer's and dementia, but a huge number make caregivers and not specific to dementia. But I certainly agree with your point. It's your perspective – what Mark said, it's really interesting because it's – Mark has suggested a different perspective and one that I think is good.

If I understand you, Mark, you said that start with the – what you want focus on in terms of important areas for measures and then we'll look at the measures. That's not what happened in AD-MI. In AD-MI we we're looking for anything that's available and then flooding them in to the areas that the bubbles that we created which we considered important areas.

So I think that Mark's idea is good.

Karen Johnson: OK, anything else on that?

David Reuben: Let me just add to Katie's comments about the schedulers. You know, there aren't – I haven't seen that much in a way of measures about that. But some of the work we had to do for the – UCLA Alzheimer's dementia care program, we really had to explore what's going on with these caregivers, the baseline.

We're finding a number of dimensions which there's a lot of variation in terms of confidence, et cetera. And these are actually things that could be operationalized into measures. You know, they’re measures now, but their constructs and questions that could be operationalized.

Katie Maslow: So – the AD-MI report, you will see that that's an area that everyone considered important. At this time we didn't find any measures, especially in use and especially reported by the caregiver, which I think is important. But we found a source of those ideas.

And then just one other thing, what you just said made me think, your project, the Indiana project and other ongoing work may have develop measure that we didn't find and might be a good source.

Cyndy Cordell: Katie I'd like to just echo what Dave said. We are currently thinking about caregiver measures for hospice. And one of the things we are asking with family members to report on in front how much training and support had they received on key process of care, in the roles of caregiver? And we're starting to see some very good variation and applying to have sort of a new measure for the field to use by next week spring.

But I think if there's some more approach to be taken to looking at Alzheimer's and think about what are the key process are and ask about how well various health care providers do in supporting the person in their roles of caregiver and how well do they do in providing the trainings that allows them to act as the caregiver. And I think that might be a strategy that would be worthwhile for pursuing.

Katie Maslow: Definitely.

Katie Maslow: And you're calling it failure to use and failure on whose part.

Joan Teno: So what we have – my own framework, we feel there's core process that causes hospice to do. So an example would be hospice needs to train that caregiver on how to administer medicine in the in the middle of the night for someone who's dying at home.

And, you know, we're wanting family members saying a rate on one side who didn't feel they had enough support in that role.

Katie Maslow: This is Katie. You know, I – that sounds wonderful to me Joan and I think that this is a really important need to – what I was saying is just that there is inventory of caregiver measures reported by the caregiver that is a basis that you could use for looking for available non-dementia measures that could be adopted. But what you're saying sounds great.

Also, I just have to say that I was appalled to find in the United States no measure, no dementia measure reported by the caregiver not ever asking the caregiver. That's more appalling to me than not asking the person even. It's just unbelievable to me that we don't have that.

Penny Feldman: Katie, this is Penny. When I was reading the paper and I don't recall this one particularly, but you turn the heaps of – the scan turned up. It seems to me, heaps of research measures that one caregiver reported outcomes of all compliance.

And you know, this raises this whole discussion. And when I was reading that, it really – you know, it's been really a number of years since I've been on in NQF Committee.

But, isn't that the case that some of these research measures have, you know, really quite a bit of evidence supporting their validity and reliability. And it's true they haven't been used in, you know, for accountability purposes. But they have clear instructions about how to use them and so forth.

So, I guess I need to be refreshed on why it's not possible to borrow from the research measure literature. And particularly, this area is so replete with such measures rich area.

Katie Maslow: I think that they're a very good source of measures and that the – and the responses of NQF, someone just answered this. My perception is that NQF looks at these kind of measures and considers what additional is needed to make them into a quality measure. Is that right?

Karen Johnson: That's right, Katie, yes. So there – what we have now, and that's one of the reasons we've provided you the recent report that we did on patient-reported outcome. So we have to start with a valid and reliable instrument or scale. But then you have to take that next step and turn those items or something into some kind of performance measurement.

So I think that might be that might be what might be lacking maybe.

Penny Feldman: Thanks.

Cyndy Cordell: Yes. And I don't know if we want to get into and one of the reasons I think that caregiver quality measures aren't implemented that often is – at least in the medical realm there's no reimbursement to talk with the family or the caregiver. So, if your going to measure something, then it might be difficult to, you know, if somebody's not doing it, how are you going to adjust them to do it?

Gail Hunt: Actually reimbursement for – under Medicare for the physicians and primary care doc to have discussions with the family as long as the patient is there. There is actually reimbursement to that.

Joan Teno: And the other thing is, as we change the as we change the inaudible in our health care system, it might behoove health care providers to spend more time talking with families in a rural to avoid hospitalization.

Cyndy Cordell: No. I totally agree. It's definitely needed.

Joan Teno: Yes. I know we don't pay for such thing. Indirectly, we may be paying for by setting up our financial center.

Penny Feldman: Yes. I think incentives are changing rapidly. And if we're forward thinking, we are to pay attention to that.

Cyndy Cordell: Yes. I have another conference call to go to, I just want to inaudible this is a fascinating discussion. I wish I could stay on, but I actually have to hop up to another conference call on the front to reading the notes inaudible that you guys present

David Reuben: Yes, I may have to break off too.

Karen Johnson: Thank you too, David. We appreciate you guys joining us.

David Reuben: We'll talk more. Thanks. Bye-bye.

Karen Johnson: OK. Thanks.

Karen Johnson: Bye.

Mark Snowden: Mark here. Since I work with scanning measure, I think the important thing for me is that not all measures that work in the research will really work when you're trying to scale them to practical practices. And I think that's going to be other thing to keep in mind. I'll have to look at their report to see what you found. I know Sue Morrison from our shop here at the University of Washington has developed a very nice, simple caregiver measure that she uses to touch on a number of different caregiver domains that I think are important.

Karen Johnson: I hope, you can share that.

Mark Snowden: Yes, yes.

Gail Hunt: Yes. I would look forward to seeing that because I know there is a quite a bit of discussion right now about how there should be a caregiver assessment actually to – in getting caregivers' input to the care plan and the care for, not necessarily for person with dementia but for Medicare beneficiaries in general.

Katie Maslow: This is Katie. There also are what I think are a really nice interest for family caregivers in the English language, non-U.S. literature. So they're a good model too that at least they've vetted for, as Mark says, towards looking at quality.

Karen Johnson: Well, Katie, let me …

Karen Johnson: Katie, this is Karen. Let me make sure I understand. Are you talking at the actual quality measures or performance measures? Are you talking about …

Katie Maslow: Yes.

Karen Johnson: OK.

Katie Maslow: I'm talking about quality measures. So there are some – if you look in the appendix and the table of non-U.S. measures, you will see some, like Gail has talked about, assessment measures, measures of care planning, caregiver involvement, those kinds of things, so. They're not – all of the measures that I think David was referring to looking at – or was that Joan was referring to, they're not that detailed but they are stored I think.

Karen Johnson: So, this is Karen again. And first, I wanted to just make sure, are you guys that are still on the call, are you able to stay for the remainder of the hour or we're going to need to try to finish off so that you guys can go to other call to

Gail Hunt: Yes. I have to get off in just like three minutes.

Karen Johnson: OK. OK. I'll try to talk about most inaudible. So, let me put out just a couple of things before you will have to leave for sure Gail.

One thing is on – here in NQF as you know, one of our must have criteria is the evidence side of things. And there is – the radicals that we know are important to do in care. But there might not be the – that's only evidence-base for accountability kind of measures and that sort of thing.

So, I just want to make sure that everybody has that in the back of their minds as we're thinking about this because that might be the potentially more of the ways that we might want to prioritize measures. So that's just to see the framework section. And I know we will have time to at least to continue on very long. But we've get started in a few things that we thought might help us start think about prioritizing.

So, things that – measures that can be useful for accountability and quality improvement, is that what we want to think about to having a solid evidence-base enabled, you know, these things, these process, particularly, would actually improve outcomes. And those outcomes don't have to be, you know, health outcomes. It could be quality of life and that sort of thing as well.

As we've already stated, outcome, you know, having the for outcomes perhaps, we've already talked about specific sets of broad population and setting. And we know that that's – we can only do so much given their current system right now. And then, as we've heard already, there's an individual about health care is provided, looking to the warnings of dementia .

So, we want to get your input as we go through on, you know, lead and what are other ways to think about prioritizing measure and how to – you know, how do we figure out what are the best things to focus on.

And, one thing I do want to say, who you have to . We have to communicate with you guys in some way. We only have this call and then we have another one, I think, in February with the Full Committee right to it. But in the meantime, we will be communicating a few often I think.

So we have a couple of options, one, specifically through either quickly convene and send or e-mails. And we have another option through a SharePoint site doing potentially discussion threads. I don't know if you guys have had – we've had little success in getting folks to actually contribute to this but we're very much willing place out there if you guys think that might be a way that you would prefer to communicate here. So they're always saying kind of trend as opposed to trying to find an e-mail. They will find e-mail for maybe really quickly. We can get your feedback on that and then we'll circle back around to prevent .

Katie Maslow: So, I prefer e-mails to offer that discussion.

Karen Johnson: OK.

Katie Maslow: Because I think people don't do it.

Male: Yes. I'm guilty at that. So I wish I did better but I know I don't.

Female: Count me in. I mean even if I – even if you send an e-mail reminding us to go on, it's one additional – the last .

Female: OK. OK.

Female: OK. OK, that's very good to know. Yes. We tried it before and I want to say this has been a failure, but – so what we're trying to do is come up with some way that we can and sent that, you know, this is the particular trend and we're trying to at least make it very obvious and maybe even narrow so that everybody can reply to those and we'll see what we can do. I mean, it will be a logistical challenge. But there's just so many things that we need to be .

Female: And I was – you know, I'm looking at this prioritization, I will say at least in our work, unfortunately there's not a lot of measure that measures outcome with this to the - so I think that's something that's, you know, we struggle with because unfortunately, you know, there's – there's non-treatment and – prior to get outcome first in the process.

Female: I agree with that, but I think that as we're talking on the table, it struck me more and more that the outcomes that we've been worrying about are outcomes related – that has been used in a pharmaceutical context …

Female: That is the medical model, right?

Female: Yes. And that this other, if you think of the first experience of care and family experience of care, I think that we could – maybe we can't come up with measures, and truly, we can't come up with already validated measures that doesn't exist. But I – isn't it true that we are looking at gaps here and that we could prioritize that area?

Female: We just made Deb very happy.

Female: OK.

Female: Because, yes, that – and I think that's kind of where we're hoping that this project will really build out what has already occurred within . You know, what is the pathway forward for development? So, yes, so that takes this natural question of what are the outcomes. We know it's not mortality, they have terminal disease. What are some of the, you know, maybe the patient reported-outcome and, you know, is it, you know, even for providing onset to our nursing facility. That might be one and I know that's the that we need so many performance measures so far that we've seen.

Female: Avoiding potentially preventable hospitalization , one of the healthy people once. That would be wonderful for people with dementia as experience of care a kind of a …

Female: Right and I think I mentioned that just to get NQF in thinking that this is – it's not easy to fit into the typical outcome measures that are out there in the medical model.

Female: Right.

Female: But having us and NQF work on this ideas, I feel like no one is paying attention to this issue except for some researchers, the Alzheimer's Association, but it's not really getting very much attention. We're stuck thinking about can we change cognition, which would be great but we can't right now. Can we change functional ability, you know, core functional ability? Probably not in most of these conditions. But there's one key to change, we have evidence research. So you can change, you know, the person's experience in ways that are important I think and so …

Female: No. And I agree. And how many people in the medical field say, "There's nothing you can do." And that's just, you know, and that's where we say, "There's so much you can do." But in their mind says, they can't, you know, they can't give a drug that really, you know, does something. So I think that is that shift of thinking and it's not an easy one to shift.

Female: Right.

Jane Tilly: I had a thought – this is Jane – one of things that I saw and I believe AD-MI work was – it seems to me, one of the priorities to think about might be taking existing well-validated measures and measuring the experience of people with cognitive impairment or dementia. And so there are some issues around identifying these people and differentiating them from the rest of the group but at least you already have validated measures. And I think that that's something that I think would help us move forward in some areas without having to reinvent the wheel.

Female: I agree.

Deb Potter: This is Deb. I'm just throwing this out, it's actually for the folks at NQF who are trying to help drive this shift. And that is, maybe it would be helpful for our advisory panel to give some thought to the outcome. And so we've talked a lot about focusing on them and maybe getting them, OK, this is my wish list and this is my wish list, so that we at least can begin that conversation because we didn't have much time .

Female: We could do that looking at both the family and the caregiver …

Deb Potter: Right.

Deb Potter: Right, right. Right.

Female: That would be great. I agree that would be really good. And …

Deb Potter: Right.

Female: But outcomes can also be appropriate to say in a Kyle McGill organization or for a plan and so, you know, we're putting everything on the table here and asking you to like help us narrow it down but to tell us OK, there's this but there's all these stuffs and the department should prioritize in this way because we know there's so many gaps.

Jane Tilly: Can I just – this is Jane. I'd like to add one topic about we haven't really discussed, and I noted on the model under the populations at risk, I do think certain minorities have higher risk acquiring dementias than others. And I'm wondering if maybe that was reflected somewhere and I didn't see it or you conceive to that as part of the populations at risks?

Female: Right now, it is really more of a – yes, we didn't really have it written down yet. Yes, other than this and the NCI, which I don't know what to do then.

Jane Tilly: OK. It's not minorities and certain minorities.

Jane Tilly: Then I lack for sure. I don't know the literature well enough to know about other groups.

Female: Yes. I think it was the 2010 facts and figures in the Alzheimer's Association focused on the different ethnicity and race. That has a lot of good data in there.

Female: And then some other thoughts that we haven't talked about, which is that not everybody with Alzheimer, I know everybody know this, but I just need to state the obvious, Alzheimer's is going to have a caregiver. So there maybe – and I don't know how to deal with that issue in here, but it is part of your model I think. And particularly, as the baby's malnourished or moving, you know, it's I think fewer children, fewer marriages.

Female: And again our 2013 facts and figures focus on that.

Female: OK.

Female: Actually. That – so every facts and figures, we have special section and that's the 2013 was about the population that truly doesn't – they don't have family caregivers but they want a caregiver. It has to be .

Karen Johnson: So this is Karen again. I really want to encourage you to at least start giving your feedback, you know, on this e-mails and that sort of thing and taking into account what is already said. This model that we put together, you know, what we – and that may not look at all like the sample diagram which is kind of a linear trajectory. It may be something very, very different. So feel free to, you know, fill boxes and draw lines and use or what, you know, whatever. Any kind of advice that you can give us to show all these things. Because right now, I don't know if we could . I don't know where to put NCI. Maybe we don't in our contextual model that I don't, you know, those are the kind of things that – that I have questions about, the Down syndrome population and then some of the – And then the other thing that Windy alluded to and maybe this is – you know, I don't know what it looks like but you know, we've already talked about workforce types of measures and things like that, you know? All right is there, you know, is there boxes for outcomes and boxes for workforce, you know, pictorially.

Female: I have like another question. I think those models are great pictorial representation so I'm not meaning to be critical at all. But usually, we have very complicated model for this. Sometimes simplify them and then have explanations with some of the stuff.

Female: It – it kind of goes what – this is probably – well and I hope everybody at least understood that the – the stage one, two, and three bubbles here, I didn't mean to have four bubbles for that.

Female: Right, no, I understood.

Female: What we've had mostly had been something very much like this but maybe, I think heart maybe AMI might be one of them, where there were four different trajectories and I can't remember why they have four different trajectories but they had different arrows and kind of showing different things, so that's one way that you could do it. I know in the – in the other trajectories they're doing contextual models. You know, it may not even be a bubble diagram at all. So and often there are other boxes that kind of show different things, so, you know, we have no limitations whatsoever. It can be whatever we want it to be.

Female: Some of the person-centered models I've seen have actually had the person at the center.

Female: Yes.

Female: And then the centric rings which I think is a different …

Female: Yes.

Female: … approach from the – I don't supposed that it's right, it's just …

Female: And what, what you're describing there. What I alluded to you very quickly. The MCC model which you know, was built as really as the next generation of what we call the care model.

And, I think the only kind of difficulty I have with that one is, it doesn't – there's – there's no longitudinal kind of flavor but if you could kind of have to – you know, I think of it is, the if that's the hype. We kind of alluded, skewed in a ballpoint for you to permeate and – so pictorially it doesn't quite get you Yes, yes, so we have to figure out, you know, the …

Female: Yes, I know.

Female: So it's hard.

Female: Yes, I agree. It's hard. And then this person-centeredness, the unfortunate, you know, outcome of what – what this disease is, the person that is lost. And so it's not just, it's difficult to person centered care, when the person can't express what they want. And so we can say that a person doesn't get Alzheimer's, a family or you know, a unit get Alzheimer's which is what David Reuben says early on. So it's – it's you know, sometimes you just can't overlay some of these persons centered thing because of that that they lose out that, it's difficult with this population.

Female: I don't agree with that, what you just said, I – I don't think that the person with Alzheimer's disease loses their person, that they have different ways of communicating what's going on with them as the disease progresses. So if you're in the advanced stages and some – I'm just going to use pain as an example. And your – you're reacting when somebody's trying to give you care by pulling away or resisting. It could be pain it could fear of …

Female: No, I totally – I totally – I totally agree I guess it's, they can't direct their care.

Female: That I agree.

Female: No, I think – I think we both – I agree with you, they can definitely show responses that can help with the interventions and all that. So I think I might be misstating but oftentimes even legislation that, you know, the person has to, you know, say something in order, you know, direct it where, you know, we work really hard to say the person caregiver or their family member because, you know, unfortunately others have to be involved in the care and we need otherwise, does that make sense? So I totally agree with you. They can express thing, they can express …

Female: It's just – I just didn't like that concept of losing personhood, I just, that I …

Female: Yes, I agree. I think that was, that was a wrong choice of words so I agree with that.

Female: Sorry.

Female: This is Katie, it seems to me that, this – this last discussion is extremely important for measure development in the sense that we don't really know on specific measure how long and which patient can answer in a valid way. We know that for a while people can and then – and then there's a point where they can't and then on the other side, we know we can always ask the family, maybe we should ask the family and the person with dementia, but each measure we would – in order to use and, particularly for a kind of accountably or publicly reported conclusions.

We would have to be much clearer than we are now about who, who answers this, and for how long? Who can answer? And when is it OK for the family to answer instead of the person when it get necessary 'cause I think the people who use them, use measure don't know the answer to that and a, we don't know, when you look at the results of the existing measures. A lot times we don't know who answer it, and that's not a good idea, a good situation. For I think it's really important.

Female: was to saying that she though that was in the CRO framework so …

Female: Right, right, this whole idea of who the respondent is and.

Male: Right, I don't know what the fields knows the answer because one of the things that's a problem is that there is durability across the dementias and there are certainly durability at the patient level. So I see patients who are the same functions, some people really can do certain decisions and some can't. I say it because say if you look at people who don't have dementias, some people are more comfortable making certain decisions than other people are.

And some rely on their families even when they don't have dementia in a different way than other people do so. I think that's partly why you don't see that. It's very hard to piece out.

Female: It seems like if we – we can't solve this but if we can make the vision more precise and increase understanding about it that would be a step forward. So what you said to is helpful and one idea that needs to be in that mix of understanding better who can answer, who can't answer, you know, that kind of thing.

Male: Yes, yes.

Female: This is central to in a sense a bad wording but, to – to making the measurement of that patient and caregivers center, we have deal with this question.

Karen Johnson: This is Karen and this is my ignorance speaking, but right now, the conceptual model that we put in front of you is just kind of the dementia contextual model. And they worry about the different types of dementia then you alluded to that a little bit with treatment options and stuff but …

Female: Well, just in terms of for me it goes beyond dementia, it goes earlier to mild cognitive impairments, which not a, I think a lot, what kind of – just sort of a concept, what I worry about is that everyone that comes into a primary care practitioner, and starting to forget things, somebody's going to say, you have Alzheimer's disease, and so I worry about detection to get those people actually into the primary care center and then I worry about, or is the primary care practitioner is going to screen out things like depression that can mimic dementia. Are they going to know that a person have a hearing problem and maybe can't convert that might – they have a, I'm making this up now, because I'm not a practitioner, they have B-12 deficiency?

I'm getting well beyond my areas expertise so that you rule out those things that could mimic dementia. And then, once you figure out, that time when it's likely to happen then you have to figure out what type. And I think all of these things are not very well done in the primary care setting. And so, that and that's critical really to everything that follows, whether it's medical care or long-term care or prevention issue. So, like if it's vascular dementia, there are things you can do to help reduce risk factors for stroke, but If you don't know what vascular dementia and you think it's Alzheimer's maybe you're not doing the right thing for the patient so.

Male: Right.

Female: Underlying concern.

Male: Yes, I think at the model level, it doesn't require that degree of specificity because I think as long as bubbles still talk about diagnosis and management, that will leave plenty of room to say that the diagnose and the management of the different types of dementia will differ and that if we really try to get choose specific about all those, it will become sort of unworkable. I would do the same thing with early onset. I don't know the in and off itself really an onset. It has to be treated separately. I personally would take NCI out of the model because I think it complicates things in a way in terms of the trajectory from a science would much more confusing than helpful.

And I think my impression as a person who works in primary-care at the time is that they are not likely to diagnose somebody with MCI with a bunch of anything. I think they wait much longer than makes the formal diagnosis of dementia than is necessary

Deb: This is Deb. I just want to clarify, make sure I understand. What I thought I heard a couple of people say earlier was that maybe we need to sort of start, not necessarily at a diagnosis but when a person in your family say to the primary care doctor, "I have trouble remembering." And that's sort of before the diagnosis, before any diagnosis whether it's recognizing sentence. But did you just say that you–we should sort of move it forward and start with a formal diagnose? I'm just trying to maybe I misunderstood?

Male: That's my opinion.

Female: That's what I think that at least you know.

Male: The MCI is very different than what you do when you have enough information to say that this person has dementia. From a public health standpoint I think it's really important to keep those straight. If we stared treating everybody with MCI or who worried about MCI as if they have actually have dementia or in fact they're going to develop dementia and it will be fighting way beyond where the evidence is really is.

Female: I think so that's – the current measures are always from point of diagnosis and we know that a very large group don't get that diagnosis. I, you know, maybe where we can put bubble is that whole detection that there's a problem. Now it's the problem–MCI is the problem, they ask, you know, I think this whole concept needs to really make people understand that you just don't do a test and may – if person has Alzheimer or whatever. There has to be this protection, there's a problem – there's a problem of cognition.

What's causing it? Is it depression? Is it, you know, vitamin deficiency or whatever it is. There has to be this detection and what happen is there's a lot of people say to their primary care physicians, "I have a problem" and they're not evaluated and we know that happens. And I think that's where if we have no measurement before diagnosis then were –we're leaving out a whole group of population that's – it's not been evaluated or not getting, you know, and again this is the association, you know, whole mantra, the earlier the detection, the earlier you get educated, the earlier you can advance plan and on .

Because we hear from, you know, date of, you know, people go in "I have a problem. It’s a menopause. It's a staph." They don't do the full evaluation and there's a lot of dissatisfaction with the timely diagnosis that takes from two, three, four years to get that diagnosis.

Karen Johnson: This is Karen and this is one of the things that I was confused about as we were trying to base some just real basic research. Research, strong evidence that the only detection or diagnosis I guess, early diagnosis actually improve outcomes. I mean logically that they have evidence being at study even observational or anything.

Male: No.

Female: No.

Male: The U.S. Preventive Services Task Force just said that instead of .

Female: No. They said there's no evidence. There's a big difference there. There is no evidence for against screenings. Not that …

Female: You know there is something in this that I've been thinking about the article says, I don't forget where it has now. And there's something that underlying a little bit, deserving about it so that if you think over the kind of study that would have to be done in order to show the evidence for the question does detecting and screening does detecting result in better outcomes. You would have to take a population and – somebody would have to do a series evaluation of everyone say over 50 in that population and determine whether those people have cognitive impairment and then probably do the diagnostic evaluation.

These I mean huge cost but then not tell the physician that that happened because you would have to watch them later and see whether those people do better or not when they receive the people that were found in this initial test to have dementia. You have to see what happens to them. That's the kind of research that ethically can't be done and would take forever. So the concept that the – we need to approve that it makes the difference. It just seems a little bit absurd to me that – of course if people – it's a same kind of question. Let me just give an example, let say that, that does it make a difference whether you recognize then diagnosed cancer or not? Well of course no one, you know, has undiagnosed and unrecognized cancer is going to get any thing.

And that's true for dementia also. They're not going to get any dementia related care if the slot – at least detected and hopefully then also diagnose. So there's a little bit of sort of strange – what I think is, you know, logical about it …

Male: The different I see is it's trying to say in the evidence for detections such that we should go out to detect it even if any no one is potentially concerned and so I would argue very important that the way to get at it is not necessarily through universal screening of people who may who made that concern.

Certainly if a person comes in and said that they have a concern about something, there should be an evaluation that would lead to a diagnosis.

Female: To me that's the point .

Female: And I think, and I also want, yeah, and I also want to try that study too, you know, we do have outcomes quality of life and things about early detection and early intervention but it didn't reach the level of evidence require by the U.S. preventive Task Force report. So, you know? So when we say things, there's no evidence frustrating as Katie said we understand that to do this types study is a longitudinal type thing. We don't know if somebody earlier enough that they get educated that maybe at their end of life, you know, they have advanced plan, all sorts of things nursing home placements, things like that. It's a huge study that would and ethical study to meet the level of evidence required for U.S. Preventive Task Force. So I think, you know, that's, you know, the poll is either

Female: I agree.

Female: Yes. A case finding and things like that. I think that's …

Male: I guess the other way to think about it is that the burden really are proof of the detection but on a treatment because you could say at the end of the and they have said the exact thing, you know, about depression for years and years. And what really change wasn't that we got better at detecting depression but we focus much more on treatment of people who are recognized and we don't about universal screening but we said, he have a complaint and you are recognized.

What do we do to the treat and we've been focused on making the treat with more effective so that in fact it paid off to actually detect. So they've actually teach what they say about depression not because the screening got any better.

Female: So, they are I think that that's a good way to put it but they're, I think we have the issue we're talking about earlier in terms of outcomes. So the outcomes that you would count, if we have more patient experience of care, family experience, those kind of things, those outcomes if we had more focused on those and less focus on – do you expect that by identifying a person with Alzheimer's disease , you're going to change that person's cognition a this point or their ADL declines.

No we don't. I don't expect that. But I do expect that we can do something for them. And I think that it's sort of obvious that if we don't detect and diagnose them, we're not even going to try. Why would we? We don't know that they have anything wrong.

Male: That's right, and I'm all for that. All I'm saying is that I don't know that we have to start this process at the universal screening point. I think there is another point that we are – there is a concern. And we talk about when there is this concern this is what should happen. And there should be an outcome both of a process. And I think this is where the cognitive domain comes to helping .

Our cognitive outcome beyond the diagnoses is a domain of particular interest. I think it's an extreme interest when we're trying to talk about detection. That I'm trying to say the detection isn't important but I do think we have to start at a point that is workable.

Female: Well, as a point, have you all – I had to step out of the room for a minute. Have you all talked about what CMS is doing around training?

Cyndy Cordell: My understanding Katie, you can correct me if I'm wrong about this is that as part of the Medicare Annual Wellness visit, there is a cognitive screening requirement. But I believe it is not universal. I believe what happens is that there's symptoms then or if somebody – some concerns then the screening occurs. Is that right, Katie?

Female: No, I – well, if Katie can't answer, I can answer.

Katie Maslow: You go ahead, Cyndy.

Cyndy Cordell: Yes, sure. I was the lead author on the Alzheimer's Association recommendations for the annual wellness visit. The element on the annual wellness visit is the detection of any cognitive impairment. We did not give any description on how to detect cognitive impairment. So they left that up, it's kind of a statement that could be observation, it could be, you know, self-report. It could be evaluation. They didn't say anything versus for depression of function they said, you have to use a tool recognized by professional societies.

So they left that portion of the annual wellness visit kind of up for, you know, literally a doctor could look somebody not do anything and check that there's no cognitive impairment and be able to build for that element and that service because, like I said, there isn't a specific measure that has to be done.

The Alzheimer's Association has recommended – there's a flowchart. You know, you look at the healthcare's assessment. I mean this population is 65 and older. So they're in the high risk population already. So we're not saying, you know, again this whole sales screen of other conditions and we don't believe it should just be a screen. It needs to be an assessment in the clinical study where they can look at the history. The flowchart goes that if a person says they have no issue if there's an informant that can confirm that there is no issue whether that's a telephone conversation or in the office visit, we basically say that satisfies the element of no detection of cognitive impairment.

If in fact there is no informant we do recommend getting some type of what we called structured assessment. We've identified some tools that have been found to be reasonably useful in the primary care setting. And I also came up with the list that they've identified to be reasonably used in a primary care setting and we also find, and this is something that we're trying to educate there end value in a normal screen.

I mean if you do a mini cog and everything is normal and somebody comes back two years later and we've had these stories told then the clock is also enough, you know, it's completely abnormal that they've been able to show their patients this and it's been able to help them get their patients to go further, because they say look at some right here. And I think that's why we always focus on the failure screens without recognizing that there is a lot of value in some surveillance type of activities out there. And this is where the annual wellness visit , you know, year after year after year. There's this structured information in the medical record and all of a sudden, somebody is having problems drawing a clock where, you know, for four years they've been doing just fine.

I think there's a lot of value to that because as we know it's not a blood test for Alzheimer's. It's more of, you know, has there been change over time and I think that's, you know, that's where I think if we – there's you know, look at the AMA measures and you know, there's a lot of measures regarding that diagnoses but if we don't put any measure of this detection I think we are missing an opportunity to help get more people that should be detected and evaluated.

I hope I didn't over my discussion.

Female: It's a great, great discussion. We're getting fairly close we still have to do this open – this call up for public comment. So if the advisory group members don't have any burning to say. Maybe we'll go ahead and open that up.

Operator, can you please prompt the t participants to ask questions?

Operator: At this time if you would like to ask a question please press star then the number 1 on your telephone keypad. We'll pause for just a moment to compile the Q&A roster.

At this time you have no questions.

Female: OK, thank you. Juliet, do you want to go ahead and take us into our next step?

Juliet Feldman: We were talking that people have mentioned functioning a couple of times. Back when I was just working at NIH quite awhile ago, I remember I had a grantee who some work in finance – I may misremember as a predictor of Alzheimer's but I just – while we were talking I just Googled him. And he's been doing a lot of work still. We have the assessment instrument. He was originally saying this is one of the first things to go. And I thought he was capturing people at a preclinical pre-diagnostic level. But what I see is just more recent work has been the very mild stages of Alzheimer's.

So I just want to think and have people think about. They were talking about the different dimensions not wanting to be too medical if you will. But just further thought maybe is there anything worth investigating in terms of functioning in different areas of life? It certainly is where most of the caregiver burden is. It actually take up a lot of the care, that physical care and otherwise.

Female: Thank you. If no other questions, we wanted to just provide our advisers an overview of the present timeline for the next several months. So as we mentioned earlier on NQF is currently finalizing the roster for the multi-stakeholder committee. That will be – the draft for October was put out for public comment by mid November and will be finalized by early December. Once we have the committee seated we tentatively have our first committee web meeting scheduled for February 25th. So advisors if you could please check your calendars and let us know if this date will absolutely not work for you, we'd appreciate it.

The next major meeting that we have will be an in-person meeting, in-person committee meeting here in Washington, D.C at the NQF offices. And we have that kind of reset for June 2nd to 3rd. So likewise, if you could please check your schedules we'd appreciate it.

And then so, by that point, the – we will have the committee let – the committee meeting. We will be gathering your recommendations for priorities and we'll have a draft report that will go out for public comment in September. And then we'll have a public webinar to get feedback on the draft report. And delivering the final report to HHS mid October, October 15th

And so this just outlines what I just went through and this specifies those days again. So please check your schedules.

OK, looks like we have another 15 minutes essentially that we could talk more if you guys want to continue talking, so we're happy to talk or let you go, whichever you want it to be. If there's anything burning that you want to make sure that we did in our summary, we'd love to hear from you.

Female: I just have one quick question and was that on that list of web searches that you had for us to think about …

Female: Yes.

Female: … and you had the topic of prevention. Can you help explain why that's a topic for this disease that we know there is nothing to – out there right now to prevent Alzheimer's disease?

Female: Well, I think there is some idea that, you know, just as an example, one of the potential ways that prevention has been thinking about is, you know, based on the cardiovascular preventive measures or things that you would do would that help vascular dementia so it's not necessarily Alzheimer's that, you know, we've seen on some – there's a few papers out there, believe it or not, on things like eating fish, you know, and just some of the nutrients, antioxidants and you know that kind of stuff.

So I think in general it's pretty weak but it is a fairly – people are looking at it. So that's why we had it.

Jeanette: This is Jeanette. At the Administration on Aging, we're working with the National Institute on Aging about not preventing dementia but reducing risk factors associated with dementia and that in fact there are a lot of …

Female: Right and I totally agree with there's information about reducing risk factors and I think that – so that was my question because, you know, there is a lot of information. We have a lot of information on our website around reducing risk factors. So I just want to clarify where your mind was going with that because and wasn't – and there was a US preventive task force out about prevention, pretty well done, and I think that was about three years ago. So there's some good information on that.

Female: There's about a 700-page kind of continuum from 2008, so it’s not brand new that AHRQ funded on prevention so it's got all that stuff in there.

Katie Maslow: This is Katie. In terms of the other groups, what's up on the screen right now, so I think that – I wonder if it's possible for you to let the person-centered care and outcomes group know that we are thinking about this and that it's an important issue and anything that they wanted to say about the kinds of outcomes that could be measured.

And then the same with care coordination. One of the things that I was really struck with in doing the ADME work is that the measures that we have now are all pretty much all about specific physician actions and the group that ADME people who came to the two meetings focused more on care management, ongoing medical care management and then of course, coordinating with the community agency and the family member involvement.

But looking at that care coordination and what it means for dementia is I think it was important to the people in the ADME meetings to think more broadly than just about a measure of did you, the physician, do this or that.

So again, just alerting them or reminding them just like you did with us in the beginning but reminding them that we're working on this topic too and we are interested in what they have to say or we'd let them to pass on anything that they know or whatever.

Female: And as a matter of fact, as Juliet mentioned earlier on, we actually when we first wrote the proposal for this project. We had all the timelines, everything we do at the same time and we actually decided that that's not too smart because care coordination workforce and person-centered care and outcomes all could potential inform our work.

So we're about a two months – two to three months lag, I think, behind what they're doing. So internally, we're keeping an eye on what they're doing. We're making sure that we either go to meetings or make sure we understand what they are doing in terms of their models and their thinking and all that sort of thing. I think person-centered outcome, my understanding, they're still trying to scope their project because person-centered outcome is just huge and so is workforce and really so is care coordination.

So they're still trying to scope to some extent but once we know a little bit more about how they're scoping I think we'll have a better idea of how they're work can ours and particularly, the one that comes to mind is the care coordination side of things because actually caregiver burden was coming up as kind of rising to the top for care coordination. So it will be interesting to see if they go in that direction or they may not because again, they have to really scope down. Ours is a little easier than that were, at least one kind of condition for that. But yes.

Female: Will they assume that all cognitive issues go to Alzheimer's in their work because there is an Alzheimer's group?

Female: I don't think necessarily, no.

Female: OK

Female: No, don't.

Gail Hunt: This is Gail. Part of the way that this is structured is that the people who are working on the Alzheimer's project will attend the advisory panel meeting for those other groups. So that they're thinking from all those other multi-stakeholders will also help inform our thinking.

Female: Good. That's great.

Female: Any other question that are burning topics or do we get to go eight minutes early?

Female: .

Female: You guys said eight minutes early. OK, we'll go ahead and conclude the call. Be looking from us for lots of e-mails to get your feedback on a lot of this questions that we touched on. In the meantime we are going to be making a summary so that will help you understand and remember the things that we did discuss and we'll just kind of keep going. So thank you so much.

Female: Thank you for you time.

Female: Thank you.

Female: Thank you.

Male: Thank you.

Female: Bye-bye

Female: Thank you very much. Bye.

Operator: And this concludes today's call. This is copyright 2013 for the National Quality form. You may now disconnect.

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