

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 ZWIG, 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

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

2 8:04 a.m.

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

7 MEMBER COOLEY: I'm here.

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

10 MEMBER COOLEY: Good morning.

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

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

22 So, we actually did come to some

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

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

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

21 We want to clarify a few things,  
22 in terms of population health and those sort

1 of things. As a matter of fact, don't let me  
2 forget to come back to that --- with D.E.B.  
3 Yes. D.E.B. was going to help us with that.

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

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

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

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

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

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

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

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

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

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



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

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

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

1 put those aside.

2 CO-CHAIR FELDMAN: She actually  
3 emphasized that.

4 CO-CHAIR PERFETTO: Yes.

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

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

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

22 The example that they gave, they

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

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

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

21             I mean different catchphrases that  
22      related to the awareness and capability of

1 local community organizations to help  
2 individuals with dementia. So, actonald.org  
3 is Minnesota's website for their approach to  
4 that.

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

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

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

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

21 It's great to think, you know,  
22 this wonderful pie in the sky. But the

1 reality is, you know, it took me since 1997 to  
2 get a survey committed for hospice to measure  
3 the quality of care, despite all the problems.

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

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

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

22 MS. POTTER: Yes. The National

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

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

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

1       about.

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

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

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

22                   So, I think, you know, there's

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

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

16           If we don't have that, we're going  
17 to have such a backlash. You know, just look  
18 at what happened in the UK with the Liverpool  
19 Pathway. You know, in the Liverpool Pathway,  
20 they paid people to put people in the  
21 Liverpool Pathway by actively dying. And it  
22 turns out, hospitals in UK were putting people



1 on the Pathway without consent and that was a  
2 huge scandal.

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

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

18 MEMBER HASHMI: Just a quick  
19 point. By no means am I an expert here. But,  
20 you know, I heard about transparency. I heard  
21 about the payment incentives need to change or  
22 need our changing. And, then, not to put away

1 the, you know, sort of put on the parking lot  
2 the community or the social metrics or  
3 measures that are important, that are going to  
4 drive some of the changes.

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

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

19 MS. JOHNSON: You go.

20 MEMBER TANGALOS: Last night, when  
21 we were just waiting around for George, I was  
22 thinking about what would I do as a consumer

1     advocate? And, so, this discussion is moving  
2     in that direction. And, as a consumer  
3     advocate, I'd be very upset about every  
4     facility out there that's assisted living that  
5     plasters a name on it that says, this is  
6     memory care.

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

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

22                MEMBER MASLOW: This will be

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

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

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

22 And, if those entities knew there

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

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

8 MEMBER MASLOW: Oh, I'm sorry.

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

11 MEMBER MASLOW: I'm sorry.

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

19 So, from inside the Department,  
 20 you never know how holes are going to get  
 21 plugged. And it may not line up at all with  
 22 what you think on the outside. But that's

1 just the way large organizations work, whether  
2 they're a hospital or the Department of Health  
3 and Human Services.

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

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

11 MS. POTTER: Sure.

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

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

22 And community could be defined in

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

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

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

20 So, it is possible to take the  
21 denominator from survey data or census data  
22 and, then, have something else at the

1 numerator. That's one way to go about doing  
2 it.

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

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

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



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

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

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

21                 So, I view, again, an entirely  
22                 aspirational perspective, that you should be

1 starting early and our goals should be not  
2 next year but 20 years from now. Trying to  
3 convince people of that, well, we have to  
4 worry about our progress over quarters rather  
5 than over years or decades, is very, very  
6 difficult. It's a real challenge and it  
7 involves reorienting our priorities.

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

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

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

21 And what we wanted to do was just  
22 review where the voting fell yesterday. And,

1     so, these are the priorities that we came up  
2     with, by category. And the numbers that are  
3     on the slide tell you the weighted number of  
4     votes. So, this is counting, not just the  
5     sticker being there but the color of the  
6     sticker.

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

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

21                    And, then, for both the person  
22    with dementia and the family caregiver, a

1 dementia-capable healthcare system. And  
2 you'll notice that this got the most weighted  
3 votes out of anything, 31 there. And, then,  
4 shared decision making and that included  
5 advanced care planning.

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

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

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

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

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

8                   MEMBER HASHMI: Okay.

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

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

22                  MEMBER REUBEN: There are a lot of

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

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

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

15 MEMBER REUBEN: Yes.

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

22 I would suggest maybe a different

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

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

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

8 MEMBER REUBEN: Yes.

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

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

20 But, yes. What I would say is, if  
21 there is an evaluation, when you review  
22 charts, you have to look for was there a TSH

1 check and you might have to go through, there  
2 might be seven or eight bullets that have to  
3 be checked to pass that quality indicator.  
4 And here's where that specificity can come in  
5 and, then, you can add the timeframe and the  
6 documentation. You've got a frowny face.

7 CO-CHAIR PERFETTO: There are  
8 other people.

9 MEMBER REUBEN: Okay. All right.

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

16 But I think, unless it's embedded  
17 in a lot of these, I just think that's one  
18 thing I'd hate to -- I mean we know that a lot  
19 of doctors say, you have Alzheimer's disease.  
20 See you in six months. And that's about it.  
21 And, then, the ones that say, you know,  
22 contact Alzheimer's Association or other



1 resources, they do and they find some support.

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

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

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

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

19 CO-CHAIR PERFETTO: Right.

20 MS. JOHNSON: So, one quick  
21 question. Under both person with dementia and  
22 family caregiver, we have that dementia-

1     capable system with community. Would that get  
2     to that, or is that something different?

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

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

21                  MEMBER COOLEY: This is Susan. On  
22     the core dementia work-up, this raises another

1 issue that may have been in the heading of a  
2 parking lot issue.

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

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

17 With the core dementia work-up,  
18 we, at VA, have a pilot measure we've been  
19 working on that is based on the desire to have  
20 a basic dementia work-up, before a person gets  
21 the diagnosis label of dementia. And it has  
22 core components of a dementia-relevant

1 history, physical exam and laboratory tests  
2 and within a certain timeframe before, up to  
3 one month after, the dementia diagnosis is  
4 given.

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

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

21 But, anyway, that's the concept of  
22 it but it's labor intensive, because we have

1 an external peer review chart audit process  
2 and it's complicated. So, that's one example.  
3 One could, you know, without saying everybody  
4 must have exactly these pieces in their core  
5 dementia work-up, we have an example of  
6 something like that. But it is based on a  
7 chart audit process, as opposed to an  
8 automated.

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

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

21 But that there may be a way to do  
22 this incrementally, where we look for a few

1 key things and, then, work to something that's  
2 more comprehensive as automated data become  
3 available. But that, if we, at the very  
4 least, could make a recommendation that there  
5 is something that is considered a core  
6 dementia work-up.

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

15 MEMBER COOLEY: It would be  
16 possible.

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

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

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

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

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

19 What I'd like to know is kind of  
20 what was left off the table, in this  
21 prioritization because where I think, you  
22 know, these things connected to social service

1 agencies, PPOs, et cetera, all those stuff are  
2 still really important. They didn't get  
3 enough votes to make it onto this slide but  
4 those things are really important. Thomas?  
5 Okay.

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

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

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

22 MEMBER GROSSMAN: So, I agree with



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

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

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

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

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

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

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

21                    CO-CHAIR PERFETTO: Katie?

22                    MEMBER MASLOW: To Cyndy's point,

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

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

11 MEMBER MASLOW: Yes.

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

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

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

21 CO-CHAIR PERFETTO: Yes.

22 MEMBER MASLOW: -- then we would

1 have it at least two places.

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

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

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

18 So, I'm wondering if it's a  
19 wording around detection being part of the  
20 regular elder care system. I'm not sure how  
21 we work on it. But, maybe, this is something,  
22 Karen, that, when notes go out from this,

1       there may be a smaller group of us that may  
2       want to sit down and think about what the  
3       measures would be, what would be feasible.

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

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

17              CO-CHAIR PERFETTO: Mark?

18              MEMBER SNOWDEN: Yes. I was in  
19      the group that came up with Number 2 and I  
20      don't have any issues with moving the third  
21      bullet into it. But would point out that part  
22      of what our group did, and this was probably

1     cheating, but it's got a number of measurable  
2     outcomes in that string. And I'm not sure I  
3     would want to forget about the ones at the end  
4     because we are spending so much time about  
5     this diagnostic evaluation that's at the  
6     beginning.

7                   CO-CHAIR PERFETTO: Yes.

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

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

22                   I intentionally stayed away from

1 the core dementia work-up. So, none of those  
2 25 are me and the reason is I would actually  
3 argue that that concept is what drives the  
4 delay to diagnosis.

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

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

19 The last point was about the 31  
20 votes. To me, that was a vision and it was  
21 easy to vote for the vision because it can  
22 include anything I can imagine. And, so, at

1     some point, we would have to make that much  
2     more specific.

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

6                   CO-CHAIR PERFETTO:   Okay.  
7     Matthew?

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

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

20                   And I think, also, that the  
21    determination has to do with, also, excluding,  
22    you know, the presentation of symptoms as



1     being dementia related. There may be  
2     something else and we see that in the folks  
3     who would have intellectual disabilities as  
4     well.

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

14                  The other couple of things I  
15    wanted to mention --

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

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

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

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

22                 You need to do it sequentially,

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

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

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

22                So, the community aspects are very

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

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

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

22 If it's the nature of how

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

9                     CO-CHAIR PERFETTO:  Lynn?

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

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

1 particular.

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

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

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

22 MEMBER JANICKI: I was going to

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

8 CO-CHAIR PERFETTO: Yes.

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

11 CO-CHAIR PERFETTO: Yes.

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

15 CO-CHAIR PERFETTO: Yes.

16 CO-CHAIR FELDMAN: You know,  
17 looking at the blue dots and then going back  
18 to the priorities from Day 1, you know, it  
19 strikes me that, because of the concept of a  
20 composite measure with bullets under it,  
21 somehow the whole notion of the things that  
22 have to happen for the family caregiver, in my

1 mind, is more expansive and less medical in  
2 the message it conveys than what we say about  
3 person with dementia on the first page.

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

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

18 And it seems to me person  
19 centeredness, which is our blue dot on the  
20 second page, is quite likely part of the  
21 shared decision making, you know, and goal  
22 setting which we want for a person with



1 dementia and family caregiver.

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

7 CO-CHAIR PERFETTO: They would  
8 have made it.

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

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

22 CO-CHAIR PERFETTO: Agreed.

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

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

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

22                  I think you've got to talk

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

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

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

21                  So, these are things that they got  
22    a few. I didn't put the numbers in, but they

1 got a few things but not a lot of blue dots  
2 and not the 20 or 30 weighted counts but,  
3 again, some of these things that you've  
4 mentioned today. So, let's go to the next  
5 slide.

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

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

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

22 So, you had the idea of the

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

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

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

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

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

19 But I don't think we can develop a  
20 composite and it should have everything, which  
21 is, as we said earlier, a little bit not  
22 practical. And then we get to Joan's question

1 of who's accountable? Where would we say we  
2 would direct this to, if this was going to  
3 happen?

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

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

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

1       build the detail metrics.

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

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

17                      There's a assessment of who is the  
18      spokesperson for the person. There's an  
19      assessment of advanced directives. So,  
20      there's maybe a half a dozen things under each  
21      of those. But those are the kind of key  
22      elements you would need to pass a quality



1 indicator, those that have to be documented  
2 somewhere.

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

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

19 CO-CHAIR PERFETTO: That's exactly  
20 where I was going with my comment is that we  
21 don't have to dive into that and we shouldn't  
22 have the expectation that a perfect composite

1     measure is going to come out of this. The  
2     expectation is that our recommendation is that  
3     this is the direction measurement development  
4     should go in and that, if HHS is thinking  
5     about funding something like this, they should  
6     get bang for their buck here versus someplace  
7     else.

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

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

19                   MEMBER REUBEN: Yes. Okay.

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

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

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

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

1 And that was just simply a question.

2 MEMBER BARTON: Okay. Thanks.

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

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

17 So, it's not only a physician who  
18 can do the things, who can ask caregivers what  
19 they've got. Other people can do that, too,  
20 and are better than physicians at doing it, by  
21 and large, except for David. But I think that  
22 it's really important not to center completely

1 on healthcare and, then, say everything is  
2 accountable to the healthcare system or  
3 provider.

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

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

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

21 MEMBER COOLEY: Right.

22 MEMBER MASLOW: But community

1 agencies receive federal government and state  
2 government and community government funding  
3 and can be held accountable in the same way as  
4 healthcare systems can and are.

5 MEMBER COOLEY: Right.

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

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

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

1                   MEMBER COOLEY:   Good.

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

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

19                  So, there's all these entities  
20                  that you could get a population, easily  
21                  identify who they are and hold them  
22                  accountable.   What would I do?   There would be

1 a chart-based measure that would capture all  
2 the things that David was talking about.

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

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

17 I think that the amount of work  
18 that would need to go into creating that  
19 survey would be substantial. But, on the  
20 other hand, I think it's a leverage system to  
21 really start changing some of the quality of  
22 care and hold these agencies accountable to



1 the consumers and, you know, also get at my  
2 concerns about these dual-eligible programs  
3 and whether they're really, truly living up to  
4 their ideals and goals.

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

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

19 So, I do think this is an example  
20 of where we want to be very careful that we  
21 don't absolve the healthcare entities because,  
22 frankly, the healthcare entities are the place

1 where many, many people, perhaps even the  
2 majority go to get their first piece of  
3 information about this, outside their own  
4 personal network. So, we want to be very  
5 careful we don't absolve them.

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

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

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

1 got that person-centered survey.

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

9 CO-CHAIR PERFETTO: Mark?

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

18 Because, then, I think you leave  
19 flexibility. In my system, there's a lot of  
20 stuff that gets passed from the system to the  
21 provider. But then there's a lot of stuff  
22 that the system takes care of that I'm not

1 individually responsible for.

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

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

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

20 The biggest challenge is how to  
21 hold community-based organizations accountable  
22 and how to get them to share the same kind of

1 records and the same kind of systems, so that  
2 they're not working at opposite purposes, not  
3 cross purposes, but in different directions.

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

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

19 And, then, who is accountable?  
20 And, from my perspective, we've made the  
21 health system accountable, because that's  
22 where the money is. That's really where the

1 money is. And I think, having a parallel  
2 system of CBOs having their own kind of plans,  
3 their own screen, is just going to be very  
4 difficult. You're going to get fragmented  
5 care. So, that's my soapbox.

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

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

22 But, you know, it's going to

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

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

4 MEMBER REUBEN: I hope so.

5 CO-CHAIR PERFETTO: Katie was  
6 next.

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

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

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

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

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

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



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

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

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

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

1 know?

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

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

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

20 MEMBER GROSSMAN: So, it's easy to  
21 find measures, safety, how many falls  
22 somebody's had. Aspirationally, there are a

1 gazillion ways to measure whether people  
2 outside of the system should be captured and  
3 be brought into a healthcare system that's  
4 dementia capable. And these measures are  
5 there. It's not tough to find them and I  
6 think you'd probably capture lots of these.

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

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

22 And it's the kind of thing that

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

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

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

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

19 MEMBER GROSSMAN: I'm sorry?

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

22 MEMBER GROSSMAN: How do they find

1 me?

2 CO-CHAIR PERFETTO: Yes.

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

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

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

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

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

22 CO-CHAIR PERFETTO: Use your

1 microphone please. We can't hear you.

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

6 CO-CHAIR PERFETTO: David?

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

18 But that said, I'm not sure I've  
19 ever gotten a referral from the Alzheimer's  
20 Association or, occasionally, rarely, from the  
21 community-based organization. But they don't  
22 refer to specific providers. You know, they

1 say, talk to your doctor about this.

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

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

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

1        referrals as well.

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

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

16                   But I think that the detection and  
17        getting people to someone who actually can  
18        respond, that whole process needs to be  
19        considered as coming from the community by and  
20        large or half or something. It needs to be  
21        considered as coming from the community. What  
22        we were talking about yesterday in terms of



1 education, public education about what signs  
2 and symptoms there are, I think that's a way  
3 to get people for an evaluation or an initial  
4 recognition.

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

9 CO-CHAIR PERFETTO: Cyndy?

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

22 CO-CHAIR PERFETTO: Cyndy?

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

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

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

19                 And we are struggling right now  
20                 with how to add physician-type groups or  
21                 clinics with some type of criteria. We just  
22                 relaunched our Community Resource Finder,

1       which is much more user friendly. And there  
2       is a section on doctors coming.

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

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

21                      New York has actually done that.  
22      On their website, they've got specific

1 criteria. Now, granted, they're in a very  
2 robust area with really great diagnostic  
3 clinics. So, they've set their own criteria  
4 for their area on their website. And people  
5 will call them.

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

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

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

22 So, then you start getting into,

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

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

10 CO-CHAIR PERFETTO: Yes.

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

16 CO-CHAIR PERFETTO: Okay.

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

19 CO-CHAIR PERFETTO: Thank you.  
20 We're going to wrap up this section. We've  
21 been talking about this family caregiver. I'm  
22 going to give Eric the last comment on this

1     one because then we have another slide that we  
2     need to cover with these clarifying questions  
3     on the individual. So, Eric?

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

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

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

1 and do it.

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

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

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

19 CO-CHAIR PERFETTO: Thank you.  
20 Okay. So, here's the updated list on the  
21 clarifying questions with the blue dot put in.  
22 And Karen has added some questions to this

1     also. For dementia-capable, who should be  
2     held accountable? What type of measures would  
3     be quantify this? Who should be the source of  
4     data?

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

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

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

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

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



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

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

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

14 CO-CHAIR PERFETTO: Yes.

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

18 CO-CHAIR PERFETTO: Yes. Right.  
19 Okay. Does anyone have any other comment  
20 about accountability on this one? We talked  
21 about dementia-capable community and a little  
22 bit about the accountability there. We talked

1 a little bit about the physician's office.  
2 Any place that we're missing, any gaps here?  
3 Katie?

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

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

20 How are you doing with your  
21 caregiver, not just how you, caregiver, are  
22 doing with the person but how's the person

1     doing with their caregiver? So, these  
2     questions are really exciting I think and that  
3     they're validated and that they've been used.

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

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

22                CO-CHAIR PERFETTO: And, Katie, as

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

3 MEMBER MASLOW: Yes.

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

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

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

1 CO-CHAIR PERFETTO: Okay. Done.

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

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

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

17 CO-CHAIR PERFETTO: Kris?

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

21 CO-CHAIR PERFETTO: Go ahead,  
22 Susan.

1                   MEMBER MASLOW:   Yes, let her go.

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

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

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

1 measurement grid.

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

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

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

20 But, if we can make  
21 recommendations as well, and to think broadly  
22 too, because I am sure there are plenty of

1       eager vendors who would love to help out with  
2       PRO work and have innovative aps that could be  
3       useful.

4                   CO-CHAIR PERFETTO:   Yes.

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

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

18                  MEMBER SNOWDEN:   Yes.   What I was  
19      struck by, Katie, is that the current CGCAHPS  
20      has questions that are almost identical to  
21      what you said.   And, so, I would want us to be  
22      mindful that, to the extent that we can merge



1 things, it will be much better than separate,  
2 because there really is a thing about survey  
3 fatigue.

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

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

21 And, so, I am going to be  
22 departing. So, I wanted to give my little

1     thing that you're going to ask for later, I  
2     wanted to give it now.

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

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

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

22            But, in moving into new technology

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

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

16                    So, it was really appreciated.

17    Thank you. And, now, public comment.

18                    (Applause)

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

22                    MS. FELDMAN: We'd also like to

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

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

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

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

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

1 dementia-capable.

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

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

18 And, in the quality assurance,  
19 what the states wanted to do was, rather than  
20 create a new set of separate measures for  
21 people with dementia, rather, identify the  
22 people with dementia and use their existing

1 systems. And, really, the biggest lift for  
2 these folks at the state level was actually  
3 identifying those with dementia.

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

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

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

22 CO-CHAIR PERFETTO: Does anyone

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

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

6 CO-CHAIR PERFETTO: Yes.

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

9 CO-CHAIR PERFETTO: Yes, please.

10 MS. TILLY: Yes.

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

19 I do want to just let you know  
20 that this all and the conversation, actually,  
21 really aligns well with some of what CMMS has  
22 been working on in the quality improvement

1 space to improve outcomes for persons with  
2 dementia and, also, their caregivers.

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

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

19 And, along that front, CMMS did  
20 host a first listening session for the  
21 community and for persons with dementia to  
22 find out what exactly matters most. So, if



1 we're going to measure something, what really  
2 should we measure, because it matters?

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

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

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

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

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

22 (Whereupon, the foregoing matter

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

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

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

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

19                   MS. POTTER: Mark referred to this  
20      as the C and G, which is its internal  
21      abbreviation. It's physician and group  
22      survey. It's a CAHPS survey for physicians

1 and group practices. And some of the items  
2 that Katie was mentioning are included in that  
3 survey.

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

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

21 So, now we're going ---- before we  
22 go to our so-called parking lot issues, some

1 of which are really important and we've  
2 discussed already this morning, we have a  
3 little bit of unfinished business in terms of  
4 some additional clarifying questions.

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

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

22           And then it was pointed out that

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

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

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

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

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

19                MEMBER GROSSMAN: Sure.

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

1       ---

2                   MEMBER GROSSMAN: Right.

3                   CO-CHAIR FELDMAN:  -- CAHPS.

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

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

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

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

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

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

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

17 Joan.

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

22 And so, one of the low-lying fruit

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

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

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

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

16 But if I were to sort of do this  
17 on a practicality basis, I would take  
18 utilization data based on someone with an ICD-  
19 9 diagnosis of dementia and look at in fee-  
20 for-services, where's the money. Where are  
21 you going to get the biggest bang of those  
22 people covered and take a look at the entities



1 and say, where can you put in quality measures  
2 that would leverage improved quality care by  
3 having point of contact.

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

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

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

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

1       fragmented.

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

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

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

21                      But I would put some expectations  
22      on them, you know, that maybe one of the

1 things you should say is that if you met  
2 someone with a change in mental status, you  
3 need to make sure --- or with a diagnosis of  
4 dementia, that you make sure there was an  
5 adequacy of the work-up.

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

10 MEMBER REUBEN: Med reconciliation.

11 MEMBER TENO: Med reconciliation.

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

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

22 I mean, there are some quality

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

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

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

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

21 And I also want to come back to  
22 the detection issue, because it may be much

1 more reasonable to expect some very basic  
2 detection and referral on the parts -- of lots  
3 of different parts of the fragmented system  
4 than it is realistic or even advisable,  
5 necessarily, to conduct the core work-up that  
6 we would like to be conducted by the  
7 appropriate clinician.

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

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

18 But I would also turn around and  
19 say that many plans rightly or wrongly would  
20 come back and say, well, our, you know, you're  
21 constantly cutting down on our per member, per  
22 month payments. And, therefore, you're going

1 to have to, you know, take into account the  
2 extra costs of taking care of somebody with  
3 Alzheimer's or X, Y, and Z in order to  
4 acknowledge that.

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

12 Mark.

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

18 The example I would give is I work  
19 a lot with the Area Agency on Aging in the  
20 King County, Seattle area and they -- they'll  
21 have to respond to the U.S. Preventative  
22 Services Task Force. And so, they do

1 universal screening and I train them in how to  
2 do cognitive assessment.

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

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

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

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

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

6 Joan. you want --

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

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

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

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



1 patient experience?

2 Katie.

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

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

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

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

1 visits.

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

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

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

17 CO-CHAIR FELDMAN: Eric.

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

1     Disease or dementia, mostly Alzheimer's  
2     Disease.

3                     And yet when you go look at the  
4     number of Alzheimer's patients recorded  
5     through the record system, it's down around  
6     20, 25 percent. So, there's a missing of at  
7     least 50 percent.

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

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

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

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

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

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

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

22                  First of all, I'm talking about

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

4 Okay. Katie is nodding her head  
5 yes. Okay.

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

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

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

20 MEMBER REUBEN: Yes, and another  
21 reason, and this gets back to that transitions  
22 that came out of our working group, I think,

1 is the whole idea if you have somebody who has  
2 dementia, they come into the hospital, worse  
3 things happen to them in the hospital. They  
4 get delirious, their medicines get stopped,  
5 you know, they get bad transitions of care to  
6 nursing homes or home health agencies. And  
7 unfortunately the patient isn't empowered  
8 enough to intervene or cognitively intact.  
9 Basically when they go to the nursing home,  
10 they can do something about it, yell and  
11 scream. Patients who are demented, frequently  
12 they'll yell and scream, but can't get  
13 anything done about it.

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

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

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

22 MEMBER TENO: So, to go one step

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

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

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

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

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

20 MEMBER MASLOW: What you just said  
21 is what I was going to say. So, if you have  
22 70 or 80 percent of the people are not

1 identified and then you have the CAHPS survey  
2 come, it can exclude the identified people,  
3 but not the other people.

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

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

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

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



1 think there are issues that clearly would have  
2 to be dealt with.

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

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

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

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

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

22 member MASLOW: It is --- we have

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

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

8 CO-CHAIR FELDMAN: Yes.

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

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

16 CO-CHAIR FELDMAN: Absolutely.

17 MEMBER REUBEN: I know you guys  
18 agree.

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

22 MEMBER REUBEN: So, the preventable

1       one, yes, that's fine.

2                   CO-CHAIR FELDMAN: Right.

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

6                   CO-CHAIR FELDMAN: Point well-  
7       taken.

8                   MEMBER REUBEN: Thanks.

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

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

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

20                   So, frequently when patients go  
21      into the hospital and come out of the  
22      hospital, they are different than their steady

1 state and those things don't get recognized.

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

9 So, these kinds of issues ---

10 MEMBER HASHMI: So, it's more than  
11 ---

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

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

19 CO-CHAIR FELDMAN: I mean, another  
20 issue that occurs around transitions is the  
21 transmission of critical information, you  
22 know, whether it's an unstable lab value or

1       whatever it is from one setting to another.  
2       And, you know, I think this, you know, it's  
3       like transmission of a core set of  
4       information.

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

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

12                   (Speaking off mic)

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

16                   MS. LING: So, just briefly, the  
17       care tool is a standardized set of data  
18       elements that's intended to facilitate  
19       measurement, consistent measurement of  
20       important domains such as function across  
21       different care settings and really then  
22       enables that information to be understood as

1 patients traverse from one setting to another.

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

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

12 CO-CHAIR FELDMAN: Thank you.  
13 Cille.

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

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

21 Having said that, you know, there  
22 is -- some of the data elements actually are

1 already in nursing home, stem from the MDS 3.0  
2 and also from Home Health. So, there's a  
3 crosswalk there.

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

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

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

16 MEMBER GROSSMAN: I just want to  
17 insert an element of reality here that I  
18 appreciate the --- under some circumstances it  
19 clearly is the case that there is  
20 communication of information from one  
21 healthcare provider to another healthcare  
22 provider, but oftentimes there isn't. And

1     some of that lack of communication is, in  
2     part, due to education.

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

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

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

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

22                Katie.



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

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

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

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

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

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

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

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

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

1 -

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

20 People leave the hospital with so  
21 many different pieces of paper. It's just not  
22 the most efficient way to say that two weeks

1 later if you're lucky, or four weeks later, or  
2 six weeks later that's going to end up on the  
3 desk of the physician.

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

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

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

20 And oftentimes I know in the world  
21 of dementia, people go into the hospital, they  
22 get delirious, they get started on an anti-

1 psychotic and six months later they're on that  
2 still and there's no reason for it. It should  
3 have never been continued.

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

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

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

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

19 And then in order to draw  
20 attention to the dementia population, reported  
21 in a stratified way so that that's the  
22 responsibility of a health plan that may be

1 responsible for reporting this for everybody  
2 who's discharged, but they also are required  
3 to report the rate for the denominator of the  
4 patients who started off the year anyway with  
5 dementia.

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

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

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

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

22 CO-CHAIR FELDMAN: Oh, yes. Okay,

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

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

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

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

1 from there?

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

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

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

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



1 (Laughter.)

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

10 CO-CHAIR FELDMAN: David.

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

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

22 But, in fact, I mean, this is

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

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

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

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

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

1       ethereal.

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

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

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

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

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

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

19                  It's a difficult thing. The  
20                  medical system when --- as we recently  
21                  learned, there are a lot of unintended  
22                  consequences to even the best-intentioned

1 measures and a lot of ways to get around  
2 things in ways that you wouldn't have expected  
3 that will defeat the original purpose.

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

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

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

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

1 And, literally, we get daily calls.

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

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

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

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

20 And this is where I think, again,  
21 with this -- there's so much misinformation  
22 about this I rating that some physicians even

1 say, you know, let's not do it at all versus  
2 there's insufficient evidence.

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

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

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

14 MEMBER COOLEY: Right.

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

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

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

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

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

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

18              So, the screening is before that.  
19      It's people who don't have signs or symptoms.  
20      So, that's the controversial part. It's not  
21      controversial that somebody has a sign or  
22      symptom that you would know what to do, that



1     you would recognize it as, you know, the  
2     possibility of dementia as well as possibility  
3     of other things.

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

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

14                CO-CHAIR FELDMAN: Right.

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

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

21                And that is the part, Susan, that  
22     you said upon, you know, recognition or

1 detection there should be report documentation  
2 and taking action.

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

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

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

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

6                   CO-CHAIR FELDMAN: Okay, Katie.

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

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

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

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

21                  Okay. So, if that's where we are  
22                  right now, then everything else that we've

1       said in this meeting is garbage.

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

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

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

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

22                  So, Mark gave this wonderful

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

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

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

22                  Meanwhile, we know that very bad

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

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

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

13 CO-CHAIR FELDMAN: Mark.

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

20 I don't know that most physicians  
21 will really decide what they're going to do or  
22 not do based on that report. I think it has

1 much more to do with their comfort having that  
2 difficult discussion and the time they have  
3 that difficult discussion and the fact that  
4 they're usually treating a patient with many  
5 other problems that they're also trying to  
6 deal with in a very limited amount of time.

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

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

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

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

12                 CO-CHAIR FELDMAN: So, I would ---  
13                 I would like to recommend because we've had  
14                 some really eloquent language and some deep  
15                 thinking about this here, that if the group is  
16                 comfortable in the same way in which we said  
17                 we would put the core diagnosis and ask the  
18                 group to work with the staff on this, if maybe  
19                 we could draft --- Mark and Katie and if  
20                 anybody else wants to do it, to work on some  
21                 language that -- for the report that I think  
22                 that would --- I think that since we are a



1 body and a steering committee of the NQF, it  
2 would be --- I think it would probably be  
3 advisable that we address this recommendation,  
4 this negative recommendation of the task force  
5 while at the same time in the kind of eloquent  
6 language that you've put, Mark, it gives then  
7 all of the obstacles and the other issues and  
8 so forth and the different dimensions of what  
9 difference means.

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

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

19 I can't believe this researcher is  
20 saying this, but she is. So, you know, to  
21 really try to draft some language about this  
22 because, as someone said, it is the theme

1       that's lurking behind.

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

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

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

12                      CO-CHAIR FELDMAN: Right.

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

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

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

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

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

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

20                  So, it's not an either/or. It's  
21                  screen, or do nothing. And that's, to me, a  
22                  very unfortunate false argument that has been

1       made in several articles following the USPSTF  
2       report coming out.

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

10                   CO-CHAIR FELDMAN: David.

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

13                   CO-CHAIR FELDMAN: Thank you.

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

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

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

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

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

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

18 I think with regard to the  
19 specific question on this page about detection  
20 should lead to diagnostic evaluation and who  
21 should be accountable, what would the  
22 recommendations be about who is accountable

1 here?

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

5 MEMBER TANGALOS: To try to get  
6 that last piece of screening with this piece  
7 right now, the way that we've taught -- and  
8 actually when I was with the Alzheimer's  
9 Association, we -- screening was on the list  
10 25 years ago. It was a long, I mean, it's  
11 been on the list forever.

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

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

21 And perhaps 65 -- I would argue  
22 that 65 is not sufficient to define a

1 population at risk, but that patient that was  
2 in the hospital with delirium is certainly a  
3 patient in a population at risk.

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

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

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

20 I'll give you an anecdote. 20  
21 plus years ago I was on the board of a senior  
22 high-rise that was just overwhelmed on the

1 nursing home side and couldn't sell the  
2 apartment community and we would screen people  
3 coming in by asking qualitative questions.

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

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

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

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



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

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

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

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

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

7                   MEMBER SNOWDEN: A couple things.  
8                   I think the at-risk populations that you just  
9                   mentioned and that Susan was mentioning is  
10                  exactly what our group yesterday with Number  
11                  22 over there was trying to get at.

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

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

22                 MEMBER SNOWDEN: That's true.

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

3                   MEMBER SNOWDEN: That's true.

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

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

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

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

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

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

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

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

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

21                  Risk factors, I was looking at,  
22                  you know, one of the articles that people are

1 talking about right now on dementia screening  
2 indicator. Risk factors such as -- and this  
3 is Deb Barnes and colleagues -- age,  
4 education, strokes, history of strokes,  
5 diabetes, body mass index, requiring  
6 assistance with money or medications,  
7 depressive symptoms. So, those are a variety  
8 of things.

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

13 The type of things that we have in  
14 our list of warning signs are things that  
15 providers might observe, that patients might  
16 report, and there's a list of those like, for  
17 example, being a poor historian, unable to  
18 give a coherent history, failing to keep  
19 appointments at the right time, repeatedly and  
20 unintentionally -- family unintentionally  
21 failing to follow directions like on  
22 medications, explain to the caregiver or

1 family member to answer questions or that the  
2 patient or caregiver might report that the  
3 person is asking the same question over and  
4 over again, becoming lost, not able to follow  
5 directions, confused about time, people,  
6 places, blah, blah, blah.

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

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

22 And to me, that's an emerging

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

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

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

18 The other side which is the  
19 detection based on person already having signs  
20 and symptoms, signs or something that they or  
21 the providers would observe or that the  
22 patient would report symptoms, that's the part

1     that, to me, is not controversial in that if  
2     we could get providers and individuals and  
3     families to at least address people who have  
4     symptoms, you know, that would be good, you  
5     know, aside from the issue of let's look for  
6     people who have cognitive impairment even  
7     though there's no overt signs, that's the  
8     screening side, you know.

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

15            CO-CHAIR FELDMAN: so --

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

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

22            And, I mean, if people -- Mary was



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

11 So, Mary.

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

21 And yet having recently reviewed  
22 the literature on this for the purpose of

1     trying to design eMeasures for CMS, many of  
2     the things that we have talked about that have  
3     logical sense and they're comforting and there  
4     may be one or two studies that have shown a  
5     risk factor in the range of, you know, two to  
6     three and a half, which is not enough of an  
7     odds ratio to really distinguish a population,  
8     unfortunately, there are -- I would say that  
9     there are two tools that have been created  
10    that neither of them have been replicated, to  
11    my knowledge, and only one of them is probably  
12    feasible for use in primary care, that tries  
13    to string together, you know, an index based  
14    on these kind of risk factors that might be  
15    knowable from history.

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

22               CO-CHAIR FELDMAN: Right. That

1 would be real gaps, right.

2 MEMBER COOLEY: I would agree.

3 CO-CHAIR FELDMAN: Great.

4 MEMBER COOLEY: Emerging area  
5 definitely important.

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

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

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

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

20 People go that? Okay. So, I  
21 think we should try to plow through these  
22 issues. And if there are areas that we think

1 we have touched upon already and that we can  
2 just move on, we should do it.

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

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

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

20 Razia.

21 MEMBER HASHMI: Just a quick  
22 comment. From my perspective, the discussion

1     about community -- agency and community  
2     measures covered it for as far as social  
3     systems are concerned.

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

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

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

22                   Razia.

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

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

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

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

21                  CO-CHAIR FELDMAN: And I -- it  
22    seems to me this is probably an area for

1 structural measures as well.

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

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

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

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

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

21 MEMBER FRISS-FEINBERG: Right.  
22 It's the performance of states. What are the

1 measures and indicators of the high-performing  
2 state system of long-term care. Long-term  
3 care being from the family home to the nursing  
4 home as we talked about yesterday.

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

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

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



1 I guess you'd call them structural measures.

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

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

10 Katie.

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

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

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

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

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

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

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

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

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

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

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

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

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

21              MEMBER REUBEN: Yes, there's a lot.  
22      I mean, what tends to happen with patients

1     like this is that unless there is an  
2     empowered, generally, daughter or caregiver,  
3     that these patients especially when they go to  
4     non-primary care settings, but also primary  
5     care physicians, they get shuttled in,  
6     shuttled out and examined like meat and, you  
7     know, look at your arm, look at your shoulder  
8     and goodbye and, in fact, their real issues  
9     aren't addressed.

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

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

20                 Katie.

21                 MEMBER MASLOW: I think it would be  
22     important to have Eleanor's feedback about the

1 dementia-capable concept. So, are we looking  
2 at two concepts, or one here?

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

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

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

20 David.

21 MEMBER REUBEN: I'm still not going  
22 to try to speak for Eleanor, but there are

1 kind of a couple different levels here.

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

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

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

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

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

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

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

18                  That would just be my two cents.

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

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

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

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

17                  CO-CHAIR FELDMAN: Lynn.

18                  MEMBER FRISS-FEINBERG: But isn't  
19                  it also, David, reimbursement for healthcare  
20                  providers, too, that physicians are not  
21                  necessarily reimbursed for talking with the  
22                  family and spending that time for a family



1       consultation and how that could change the  
2       whole trajectory if there was adequate  
3       reimbursement for looking at the person in the  
4       family as a unit and talking with that family  
5       member as an informant to help in the  
6       diagnosis of the person with dementia?

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

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

19             CO-CHAIR FELDMAN: Katie.

20             MEMBER MASLOW: I don't know this,  
21      but we talked yesterday about the Minnesota  
22      dementia-friendly communities. And I know

1       that there is an evaluation happening. And  
2       I'll ask the evaluator and let you know  
3       whether they are -- whether the evaluation has  
4       standards in it. So, are they evaluating for  
5       certain characteristics or not?

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

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

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

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

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

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

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

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

18                  CO-CHAIR FELDMAN: Mark.

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

1 I would also add accountability at  
2 both levels.

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

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

15 What did -- do you recall what  
16 prompted that?

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

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

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

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

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

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

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

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

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

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

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

20                 And I'm not sure what the strategy  
21                 is for dealing with that other than to say in  
22                 a report we've identified six things that we

1 believe are of the utmost importance and the  
2 evidence doesn't rise to the level that's  
3 required for formal endorsement of a measure.  
4 And, therefore, we recommend that additional  
5 work be done to create this into an evidence  
6 measure.

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

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

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

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

22 And then I was excited about what

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

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

10 CO-CHAIR FELDMAN: Mark.

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

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

22 The second take I would have, and



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

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

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

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

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

1 MS. JOHNSON: Yes.

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

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

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

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

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

20 (Pause.)

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

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

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

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

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

18               So, are we going to advocate for  
19       things that have been shown and the number of  
20       quality measures are going to be much fewer.  
21       And then they -- I'm not going to say trivial,  
22       but let me just tell you a lot of the PQRS

1 measures are trivial, you know. They just  
2 don't make a big difference in the world. So,  
3 that's the importance versus the evidence one.

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

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

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

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

16 CO-CHAIR FELDMAN: Joan.

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

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

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

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

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

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

20                  So, I don't know if I'm as worried  
21                  --

22                  MEMBER REUBEN: Well, just to

1 counter that --

2 MEMBER TENO: Sure.

3 MEMBER REUBEN: -- how many  
4 dementia measures have gotten through NQF?

5 MS. JOHNSON: I think right now we  
6 have five.

7 MEMBER REUBEN: Do you remember  
8 what those are?

9 MS. JOHNSON: Actually, two of them  
10 are practically the same. They're set in the  
11 nursing facility and they're looking at  
12 diagnosis, trying to give a diagnosis in NFs  
13 based on answers to BIMS in the MDS. I feel  
14 like alphabet soup here. So, that's two of  
15 them.

16 There's an anti-psychotic  
17 medication one and --

18 SPEAKER: That's in nursing homes.

19 MS. JOHNSON: That's in nursing  
20 homes as well. And I'm blanking on the other  
21 -- actually, there's only one more and I'm  
22 blanking on that one.

1                   MEMBER REUBEN: So, out of all the  
2                   stuff we've talked about, it's like nothing  
3                   even close except in the nursing home  
4                   population.

5                   MEMBER TENO: But how many have  
6                   been rejected? I think the issue is not --

7                   MEMBER REUBEN: A lot.

8                   MEMBER TENO: Really?

9                   MEMBER REUBEN: Yes.

10                  MS. JOHNSON: Yeah.

11                  (Speaking off mic.)

12                  MS. JOHNSON: The AMA ones went  
13                  down.

14                  MEMBER REUBEN: ACO, all these  
15                  things have been put together and are  
16                  evidence-based ones.

17                  MS. JOHNSON: And those were  
18                  process measures and many of them had to do  
19                  with assessments.

20                  MEMBER TENO: Okay.

21                  MS. JOHNSON: Which we all agree  
22                  are important, but they're very distal to that

1 outcome.

2 MEMBER TENO: So, I still wouldn't  
3 translate that experience into coming up with  
4 a patient experience measure.

5 I think -- a good patient  
6 experience measure, I think, would have to --  
7 you could build a very strong case. You have  
8 to think very carefully how you're getting the  
9 denominator. You would have to get the CAHPS  
10 folks over their hurdle of being afraid to  
11 talk to someone other than a patient, but  
12 hopefully we're working on that right now.

13 We have been talking to brief  
14 family members. So, that's a start.

15 MEMBER REUBEN: That's only one  
16 small component of what we want to do here.

17 MEMBER TENO: Sure.

18 MEMBER REUBEN: I mean, that's the  
19 conundrum. The conundrum is the kind of  
20 measures that measure this kind of stuff  
21 aren't getting through. And that's a problem.

22 MS. JOHNSON: Although, I would



1 say, I mean, like even with the support, the  
2 training, one easy process measure might be  
3 did you offer training, you know. And that  
4 may or may not get through.

5 But if you ask the caregiver their  
6 experience, did you feel that you had the  
7 skills that you needed to, you know, to take  
8 care of my loved one, that kind of measure  
9 probably will get through.

10 So, I think some of these  
11 concepts, you know, maybe it's creativity in  
12 how you construct the measure.

13 MEMBER TENO: I think the other  
14 thing that really needs to happen is how do  
15 you get the measure developer connected with  
16 the healthcare system to really do a good  
17 measure?

18 To me, what's really lacking in  
19 the whole process is the ability to do a  
20 multi-site study where you can measure what's  
21 called the ICC -- measure of the ICC so you  
22 understand how much variation and how many

1 cases you need to do to have that.

2 And that's the one thing it's  
3 really hard as a measure developer to do that,  
4 because that means you're really going beyond  
5 a small validation study, but you're going to,  
6 you know, where you're going to get 30 or 40  
7 healthcare institutions to do that.

8 And that, unfortunately, is a  
9 sizable chunk of change to do that. It's not  
10 easily done and it takes really monetary  
11 support to do that.

12 CO-CHAIR FELDMAN: So, I'm probably  
13 overly optimistic. But given the ACA and what  
14 I think are forces from many different parts  
15 of the system, I guess I'm cautiously  
16 optimistic that the likelihood of, frankly,  
17 federal dollars to develop some kind of  
18 composite support of caregiver and some kind  
19 of composite-shared decision-making could for  
20 a caregiver person with dementia and, you  
21 know, could actually reasonably come about.

22 And if we're talking about gaps

1     and we're talking about where we would put our  
2     money, we have a couple of person-reported  
3     sets of, you know, I don't know whether, I  
4     mean, we put it in terms of a composite  
5     measure to really think about the components  
6     of such a measure.

7                     I mean, I think that that's  
8     potentially where this could lead if we wanted  
9     to be very strong in our statement because we  
10    said we were talking about gaps.

11                    MEMBER TENO: Just occasionally I  
12    wake up here and comment a lot. I'll try to  
13    make this my last comment.

14                    The other really low-lying area  
15    here is to look at some of the existing  
16    measures and see if you can create a  
17    stratified analysis based on that.

18                    So, I think the perfect place to  
19    begin and to publicly acknowledge, I actually  
20    think the 30-day hospital readmission measure  
21    was brilliant. It really had a huge impact on  
22    our healthcare system when you have healthcare

1       systems now saying I'm going down from working  
2       with 90 nursing homes to only 60 nursing  
3       homes.

4                       So, you know, you could develop a  
5       measure that would really get at dementia  
6       patients 30-day hospital readmissions that  
7       just puts us on the radar and to look at it as  
8       stratified. So, I think that's another  
9       opportunity.

10                      It's a low-lying fruit. You can  
11       do it. It's already an existing measure. We  
12       just now bring it up to prominence by  
13       reporting it.

14                      CO-CHAIR FELDMAN: And we have  
15       consideration of existing measures and  
16       exclusion, slash -- I think of it as both  
17       inappropriate exclusions and important  
18       inclusions and stratification.

19                      And so, we have identified --  
20       yesterday we talked about CAHPS and the -- we  
21       talked about pain measures. We've talked  
22       about transitional care measures. We've

1       talked about the experience of  
2       hospitalization.

3                 Hospital readmission measures are  
4       having a big impact, as Joan said, on the  
5       hospital system.

6                 There are also hospitalization  
7       measures in nursing facilities and in-home  
8       healthcare.

9                 I mean, those are all areas where  
10      if we stratified for the population with  
11      dementia, it could have an impact.

12                And where I think it would also in  
13      some of those create a strong incentive to  
14      actually record the diagnosis, because then  
15      they would be stratified and, you know, so --  
16      and compared against other people with  
17      dementia.

18                Murray.

19                MEMBER GROSSMAN: So, this may be -  
20      - this is clearly a question of ignorance and  
21      this may not be the right place for me to ask  
22      it, but it sounds like we're trying to figure

1 out what kind of content is going to go into  
2 a report.

3 And I'm trying to understand if  
4 part of that report includes something about  
5 the payoff. Why are we doing all of this?  
6 We're going to save X billions of dollars a  
7 year because we are screening, we're going  
8 from diagnosis -- from detection to diagnosis,  
9 that kind of thing.

10 Does this report intend to include  
11 something about payoff?

12 (Pause.)

13 MEMBER GROSSMAN: Sorry. I can ask  
14 afterwards.

15 MS. JOHNSON: I would have no idea  
16 what --

17 (Speaking off mic.)

18 MEMBER GROSSMAN: Yeah, this, I  
19 mean, this is totally out of ignorance, but  
20 the point is we're trying to find some source  
21 of funding so that we can develop measures  
22 that we all think is needed. And so, we have

1 to convince somebody that that is a useful  
2 thing.

3 And to do that in this day and  
4 age, oftentimes it comes down to dollars and  
5 cents.

6 So, how much money are we going to  
7 save the government by investing some money  
8 now in developing these measures?

9 MS. JOHNSON: I think in general I  
10 was not expecting this report to try to figure  
11 that out and I would not even know where to  
12 start, to tell you the truth, on an ROI or  
13 something like that.

14 My interpretation of what HHS has  
15 asked us is that if they should have money in  
16 the future, where would they want to put their  
17 dollars?

18 So, we're kind of going on the  
19 assumption that eventually somebody will want  
20 to put some dollars into this and we don't  
21 have to make that case.

22 MS. POTTER: But I would remind

1 everyone that the National Healthcare Strategy  
2 has as its sixth goal, the one that gets  
3 forgotten all the time, affordability.

4 So, you know, that's part of what  
5 the Department and the ACA think about in  
6 terms of healthcare quality, you know.

7 You may not use it for quality  
8 improvement, but you might use it for  
9 accountability.

10 So, I'm not saying that what Karen  
11 said is not what would be included in the  
12 report, but just that the affordability is  
13 something that should be thought about, that's  
14 all.

15 CO-CHAIR FELDMAN: Ryan, and then  
16 Barbara.

17 MEMBER CARNAHAN: Yeah, I just  
18 wanted to put in a quick plug for the high-  
19 risk medications measure as one to be  
20 stratified, because I think it's doubly or  
21 triply important in this population. I mean,  
22 you could add a few meds, but for the most



1 part it's a pretty good list.

2 MEMBER BAYLIS: So, I'm concluding  
3 that NQF will most likely approve outcome  
4 measures rather than process. Is that what  
5 part of that discussion was with David and  
6 some of the things that I -- outcome rather  
7 than process?

8 (Speaking off mic.)

9 MEMBER BAYLIS: Okay. And then  
10 also the other point is -- it's on. Okay.  
11 And the other point is about the evidence  
12 base.

13 So, should we sort another sort of  
14 what measures are processed, which ones are  
15 outcome? And then who will do -- who will  
16 research and find the evidence? And what  
17 strength of evidence does NQF typically look  
18 at? IT's like A, B, C or whatever.

19 Is there something that is a  
20 standard for them and will we do that, kind of  
21 sort outcome and structure or process?

22 MS. JOHNSON: Well, I think some of

1 the questions that we've already talked around  
2 has gotten to some of that already.

3 In terms of finding the evidence  
4 base and all that sort of thing, that's into  
5 the realm of the development just like, you  
6 know, we're not asking you to specify all of  
7 the things.

8 So, what we're hoping for is the  
9 concepts and some direction in terms of, you  
10 know, should -- can this be an outcome  
11 measure, or does it need to be a process  
12 measure?

13 Any kind of input that you have on  
14 that, but then it would be the developers who  
15 would do that actual specification and finding  
16 evidence if they need it for process measures,  
17 that sort of thing.

18 CO-CHAIR FELDMAN: I'm sort of  
19 pondering this notion whether one of the  
20 sentiments we want to express is that without,  
21 you know, short of some cost benefit or cost  
22 effective analysis, but some kind of statement

1 about, you know, identifying people with  
2 dementia and seeing that they get appropriate  
3 care over the, you know.

4 And one has to be cautious.  
5 Because as David said, you don't want to imply  
6 that people should never go to the hospital  
7 just because they have dementia or whatever,  
8 but, you know, there are certain kinds of  
9 procedures and all kinds of things that, you  
10 know, that are probably not advisable for  
11 people particularly with advance dementia.

12 And greater attention to  
13 identifying and providing appropriate care for  
14 people with dementia is not only good for the  
15 individuals and families involved, but will  
16 have -- will have affordability benefits, you  
17 know.

18 And I don't -- I think  
19 particularly end-of-life and advance care and,  
20 you know, advance care planning, I mean, this  
21 is kind of soft, I guess, to put in the  
22 report.

1                   MEMBER TENO: I don't know if we  
2                   have to make a business case for the measures  
3                   right now.

4                   You know, I think all we're trying  
5                   to help people is to think through where there  
6                   is gaps in potential areas that we as an  
7                   expert group of clinicians and scientists and  
8                   various other roles think that it would be  
9                   promising to consider.

10                  I think as you go through this  
11                  process of measurement development, you know,  
12                  and if you want to go to national  
13                  implementation, you end up as one of the  
14                  things you have to do -- to become compliant,  
15                  you have to go through a review process where  
16                  you have to cost it out and say how much this  
17                  is going to cost healthcare providers.

18                  CO-CHAIR FELDMAN: All right.  
19                  We're just about -- it's just about time for  
20                  us to take a short, you know, pick up lunch  
21                  and then come back to finish our discussion.

22                  We have a variety of other parking

1 lot issues. Some of which I think we've  
2 really touched on directly or indirectly like  
3 delivery system change and its relationship to  
4 payment systems and publicly reporting.

5 We've talked about patient-  
6 reported outcomes. We've talked about use of  
7 non-dementia-specific measures. We had a  
8 lengthy discussion of safety yesterday.

9 I think we have not come back and  
10 it didn't -- it's interesting it didn't really  
11 surface in our priorities to the issue that  
12 was raised early yesterday when we were  
13 discussing vignettes, which is you can have  
14 this great measure around, you know,  
15 participatory and shared decision-making --  
16 it's the issue of personalized measures. That  
17 you can have all this discussion of  
18 individualized goals and shared decision-  
19 making and so forth. But if in the end the  
20 performance measures aren't in accord with  
21 individual goals, then a system or an  
22 organization or whatever is being measured on

1 a set of things that, in fact, are not in  
2 alliance with what people want.

3 And I don't -- this is, it seems  
4 to me, the last really big issue that we  
5 talked about yesterday that we really haven't  
6 come back to at all and isn't really -- I  
7 don't think it's reflected in the -- our  
8 priorities because we've put a huge emphasis  
9 on the shared decision-making and so forth,  
10 but we haven't really -- but you could measure  
11 that without necessarily changing the other  
12 outcome measures that are there.

13 So, I don't know how people want  
14 to -- if people want to take that on in some  
15 way or not.

16 MEMBER REUBEN: Yeah, I think we  
17 have to take it on. I mean, I think -- I  
18 think we have to take on a new outcome  
19 measure.

20 I think we have to take on a new  
21 outcome measure of goal-oriented care for  
22 patients with dementia, you know.

1                   It's just in an area where  
2                   existing outcome measures don't really --  
3                   aren't really appropriate or relevant.

4                   MEMBER BARTON: Don't apply.

5                   MEMBER REUBEN: They just don't  
6                   apply. And I think that can be done. There  
7                   is a science behind doing it. And I think  
8                   we're shortchanging our patients if we don't,  
9                   you know.

10                  The idea is it's not how many --  
11                  it's not like glycohemoglobins. It's kind of  
12                  this is your life. This is the last part of  
13                  your life. What do you want from it?

14                  And if we don't establish those  
15                  outcomes and measure how a system does,  
16                  performs on that.

17                  So, they have to be  
18                  individualized. They can't be generic  
19                  outcomes.

20                  CO-CHAIR FELDMAN: So, you and I  
21                  spoke kind of fervently about that yesterday,  
22                  but I don't think we heard a lot from other

1 people. And it's also the issue of how you  
2 would aggregate it up to the organizational  
3 level.

4 So, I think it's important that we  
5 just get a little bit of a sense of the group  
6 here about this.

7 Mary.

8 MEMBER BARTON: Well, I'm fervently  
9 in favor of this. And I think that, you  
10 know, one of the questions, maybe one of the  
11 ways that this group could assist in this  
12 trajectory is to find, you know, either a  
13 tool or a couple of tools that have the  
14 relevant domains in them that you could use  
15 to repeatedly administer. And then help in a  
16 shared way, discuss with the patient and the  
17 caregiver, which one of these matters to you,  
18 so that you could then individualize the  
19 goal.

20 And so, I think that where the  
21 starting point, people are like throwing up  
22 their hands, they don't even know where to



1 begin. And having either, you know, if  
2 there's a favorite tool that geriatricians  
3 know is the one that works, and I'm not a  
4 geriatrician, I don't know, or if there's a  
5 few tools that are practical to use in that  
6 kind of setting, double bonus if they could  
7 be used at home by the caregiver on their  
8 mobile phone before they came to the visit,  
9 right, and that that would be a big  
10 contribution of a committee like this to then  
11 getting developers like me engaged in trying  
12 to make measures like that.

13 CO-CHAIR FELDMAN: Lynn.

14 MEMBER FRISS-FEINBERG: As I think  
15 some of you know around the table there's  
16 been an enormous amount of work in thinking  
17 about the importance of assessing the family  
18 caregiver's needs.

19 What hasn't been done yet that  
20 clinicians ask and providers ask is, okay, if  
21 we agree that this is a good thing to do,  
22 what are the five to ten questions we should

1 be asking families repeatedly. And that, to  
2 me, is the next step.

3 That said, from a social work  
4 perspective, some of the most important  
5 questions to ask the person in the family to  
6 engage them further in thinking about the  
7 rest of their life and the quality of their  
8 life are things like what matters most to  
9 you? These are open-ended questions not  
10 necessarily -- but they're really important  
11 for quality of care.

12 Another important question that we  
13 always found at the Family Caregiver Alliance  
14 which was so helpful is, what is your  
15 greatest worry?

16 And you get good information from  
17 questions like -- what is your greatest  
18 worry? What matters most to you? Things  
19 like that, but they're not necessarily  
20 quantifiable. It opens it up though.

21 MEMBER GROSSMAN: So, I agree that  
22 I think that it's an important question, but

1       it's a very difficult question, in part,  
2       because of trying to figure out how to frame  
3       it.

4                   For some folks, the concern is a  
5       very immediate one. I want to be able to  
6       walk better. I don't want to fall as much.

7                   Other folks might be a question  
8       that's much larger in scope: I want some  
9       pleasurable way to live the next five years  
10      of my life.

11                   And what makes it more  
12      complicated, I think, is that the frame of  
13      the question from the perspective of the  
14      caregiver and the patient all depends on  
15      what's the antecedent context. So, what's  
16      going on beforehand makes it very, very  
17      difficult.

18                   Some folks have had, you know,  
19      reasonable care. They have a good life plan  
20      for their five years, whatever, and they  
21      really are concerned about something that's  
22      very immediate. Some, you know, small,

1     little concrete thing that's got to get  
2     solved and, you know, that's it.

3             Other folks haven't thought about  
4     how I want to live the rest of my life. And  
5     it's an educational process.

6             So, I think that it's a really  
7     important issue, but I think that it's a huge  
8     issue and very, very complex.

9             And I think that it may involve  
10    thinking about certain -- a question, an  
11    open-ended question, the sort that you  
12    described might be not unreasonable, but I  
13    think that we'd be much more successful  
14    getting an answer to the question if we  
15    thought about it in different ways, putting  
16    it in -- you know, depending on the context.

17            CO-CHAIR FELDMAN: Mark, and then  
18    Mary. And then maybe we'll go get some lunch  
19    and ponder. We can talk while we're eating.

20            MEMBER SNOWDEN: Yeah, I mean, the  
21    closest analogy I can come to in what David  
22    is talking about in my work is I do a lot of

1 work with problem-solving therapy.

2 And the fundamental of problem-  
3 solving therapy is that it's the patient that  
4 gets to decide what problem. I don't do an  
5 analysis and tell them, well, these are the  
6 problems you need to solve, or I don't train  
7 my care managers to do that. And you can  
8 then ask how successful was our therapy in  
9 doing that.

10 So, to me, maybe you could measure  
11 are you being asked what's important to you,  
12 what are your greatest fears, without having  
13 to get into us guessing ahead of time what  
14 those are going to be.

15 And then you can ask was your  
16 interaction with the health system or  
17 whoever, a community-based provider, whoever,  
18 was it successful in having you reach the  
19 goal you wanted.

20 And there are actually instruments  
21 that have been developed to get to the latter  
22 part.

1                   MEMBER BARTON: Well, I just wanted  
2                   to answer -- to engage a little bit on  
3                   Murray's question, but I think your example  
4                   is really perfect in saying that there are  
5                   pockets of ways that you can do this around  
6                   all of clinical care.

7                   And usually they've been very  
8                   siloes and specific, but the -- two things.  
9                   One is you started to come up with a first  
10                  step yourself.

11                  So, you said, you know, some of  
12                  the tools would need to cover short-term  
13                  goals and events. And there might be other  
14                  question sets that have to do with, you know,  
15                  a few years' horizon.

16                  So, you might set up -- so, you  
17                  might start to gather the criteria that you  
18                  would use to build something like this just  
19                  in the way that you started doing.

20                  And then the second thing I would  
21                  say is that in the, you know, the generic  
22                  version of this, the goal attainment is

1 measured against the goal that was set by the  
2 individual.

3 So, notwithstanding the fact that  
4 they're coming from all different places and  
5 they're coming with all different previous  
6 contexts, you would be assessing the success  
7 of the clinical encounter in helping this  
8 patient meet their goal, not someone else's  
9 goal.

10 MEMBER GROSSMAN: Yeah, but that's  
11 the kind of thing that lots of docs do when  
12 the patient comes into the office. They say,  
13 how can I help you today?

14 It's a very straight forward kind  
15 of question and, you know, we ask in an open-  
16 ended way -- I ask it in an open-ended way to  
17 try and learn what are the significant --  
18 some people come in with a short-term  
19 response. Some people have a long-term  
20 horizon kind of goal.

21 But the, you know, even -- so,  
22 it's important to put it in the context of

1 the individual. And they come from different  
2 perspectives and it's a tough thing to  
3 capture.

4 So, I can ask the right questions,  
5 I think, but putting it in the context of  
6 that person's previous experiences is, I  
7 think, a very difficult kind of thing for  
8 somebody to do, a doc to do in an office.

9 CO-CHAIR FELDMAN: So, one way into  
10 this or out of this might be to say that as  
11 part of the shared decision-making construct  
12 that we have asked for, that we should not  
13 only be assessing for personal treatment  
14 goals, but -- since this is something that's  
15 going to be done repeatedly over time, but  
16 also assessing as to whether the, you know,  
17 perceptions of whether a person's treatment  
18 goals are being met or, you know.

19 In other words, they're not just  
20 asking me, but is it -- does it seem to be  
21 making a difference? And that's certainly --  
22 I -- one way into the process.



1                   Joan, and then lunch.

2                   MEMBER TENO: In that case, I'll  
3                   just remind us that we can't always get what  
4                   we want, to quote the Rolling Stones.

5                   CO-CHAIR FELDMAN: Great. Grab  
6                   your lunch. I guess make a quick pit stop if  
7                   you need to, and then we're going to come  
8                   back as soon as possible because the idea is  
9                   a working lunch.

10                  (Whereupon, the proceedings went  
11                  off the record at 12:31 p.m. and went back on  
12                  the record at 12:50 p.m.)

13                  CO-CHAIR FELDMAN: Okay, folks.  
14                  At this point, we're running about 20 minutes  
15                  later than we thought, but that's because we  
16                  had such a good discussion and we identified  
17                  all the problems of the field and we solved  
18                  at least 15 of them.

19                  (Laughter.)

20                  CO-CHAIR FELDMAN: So, we thought  
21                  that we would use this last part of our  
22                  meeting as an opportunity for people to

1 reflect back on the last day-and-a-half.  
2 We've had some really probing and sometimes  
3 encouraging and sometimes discouraging  
4 discussions.

5 But, to give each person an  
6 opportunity here, essentially, to leave us  
7 with your, I don't want to say parting word  
8 because there will be additional future  
9 communications, but with what's the most  
10 important thing you want to convey to the  
11 rest of the group today as a result of the  
12 conversation that we've been having for the  
13 last day-and-a-half.

14 And I mean it's the kind of thing  
15 you're going to walk out of this room and,  
16 instead of saying I wish I had said that or I  
17 wish I had emphasized that, that you actually  
18 had an opportunity to do it. And, if you'll  
19 recall Eleanor's parting words were, in fact,  
20 the importance of identifying low lying  
21 fruit. And I think we've had a lot of  
22 discussion about that.

1                   If there is something that  
2           somebody else has already said that you want  
3           to emphasize, I would just urge you. I think  
4           that's really important to reinforce it but  
5           don't feel obligated to go on and on about  
6           it. And why don't we start over here? Yes,  
7           Katie.

8                   MEMBER MASLOW: Sorry.

9                   MEMBER STAPLES: That's okay. On  
10          the last slide under the Tests and Measures,  
11          we talked about safety. And, while safety  
12          certainly can be a pre-existing measure of  
13          fall safety or environmental, I think really  
14          safety could be not all encompassing but  
15          maybe all under-encompassing rule under each  
16          of the categories we talked about today, in  
17          that safety applies to everything that we  
18          talked about.

19                   And I just wanted to make sure  
20          that we didn't ignore that safety issue for  
21          everything from physician making a diagnosis  
22          and recommending what happens next to all the

1 other categories that we talked about.

2 CO-CHAIR FELDMAN: Katie?

3 MEMBER MASLOW: I was just talking  
4 to Bill about this for a couple of minutes  
5 and it seems to me that the point he's making  
6 is really important.

7 I know we talked about safety  
8 issues but, really, one of the things about a  
9 person with dementia and one of the fears  
10 that affect family members are safety things.  
11 So, the person's inability to judge what a  
12 risk is and all sorts of things are very  
13 important. And I wonder if we've adequately  
14 gotten that into our thinking here.

15 CO-CHAIR FELDMAN: Is that your  
16 departing word or do you want to have a  
17 little discussion?

18 MEMBER MASLOW: That can be my  
19 parting word.

20 CO-CHAIR FELDMAN: I'm game for  
21 more discussion if people want. I don't want  
22 to herd us into --

1                   MEMBER HASHMI: The only thing I  
2 would say is that that's a very important  
3 point and I agree that it should be part of  
4 the sub-domain or a running theme throughout  
5 all of the metrics.

6                   CO-CHAIR FELDMAN: I think one of  
7 the things we've pointed out here is that,  
8 you know, a lot of times when people think of  
9 long-term care, they only of nursing homes.  
10 When they think about dementia, they think  
11 about memory loss and nothing else.

12                   And, when they think about safety,  
13 they think about falls or they think about,  
14 you know, maybe wandering. But these are all  
15 issues that are multidimensional and have  
16 particular implications for people with  
17 dementia.

18                   I don't know if we're going to  
19 have definitions or something at the  
20 beginning of the report. But I think we've  
21 got lots of examples of terminology that's  
22 often too narrowly applied or words that are

1 too narrowly defined.

2 MEMBER MASLOW: I think, if you  
3 think about what freaks family members out  
4 and impart with respect to managing co-  
5 existing medical conditions, it is safety in  
6 a way. Okay? So, the person doesn't  
7 understand, often, what needs to happen in  
8 terms of diet, medications, tubes, exercise,  
9 anything like that.

10 And, so, a family member is trying  
11 to watch and be sure the person's care is all  
12 right. And the same in hospitals. What  
13 agitates nurses and aides is there's a person  
14 who, they may not know it, but the person is  
15 going to fall, wander someplace, not eat,  
16 roll over the wrong way, all of those kinds  
17 of things. They are medical safety kind of  
18 issues.

19 So, I think maybe, Karen, if you  
20 could just see, as you go through, is this  
21 there enough and that the safety questions  
22 are a problem to family and for the person.

1 MS. JOHNSON: Yes. So, I think I  
2 may need to talk a little bit more offline,  
3 maybe, with you, Bill, and make sure that I'm  
4 understanding because I think I was coming at  
5 this from the idea that we already have  
6 several safety measures and I fall into the  
7 category, you know, we've got falls, pressure  
8 ulcers, that sort of thing.

9 And, if we, at the very least, do  
10 some stratification, that would at least be a  
11 start. That may be some low hanging fruit.  
12 Sounds like you're talking about going a  
13 little further.

14 MEMBER STAPLES: And even  
15 including, you know, abuse for that as well.

16 MS. JOHNSON: Abuse.

17 CO-CHAIR FELDMAN: Also, I think  
18 this goes to the issue of why does it make a  
19 difference to detect someone and to actually  
20 record that a person has dementia because  
21 there are wide ranging, you know, sort of  
22 global safety issues. So, that's less the

1       measure-specific and more the why does this  
2       make a difference.

3                   MS. JOHNSON:   So, that would be  
4       good context.   Yes.

5                   CO-CHAIR FELDMAN:   Yes.   Yael, you  
6       have the privilege of being the first person  
7       to leave us with your parting thoughts.

8                   MEMBER ZWEIG:   So, I guess I was  
9       just thinking, you know, what was my take-  
10      away and just to kind of fill in any gaps  
11      that I thought maybe we didn't address.   And,  
12      so, I think we've talked a lot about the sort  
13      of important interplay between kind of the  
14      medical system and all the community  
15      organizations.

16                   But what we didn't touch upon much  
17      is also just importance of the interplay  
18      between interdisciplinary and multi-  
19      disciplinary collaboration and collaborative  
20      care, especially like sort of just to get  
21      back on what Lynn said.   You know, clearly,  
22      the take-away here is what caregivers really



1 want is the concrete services and the  
2 supportive care and referrals.

3 And, yet, the person who is kind  
4 of expert in that area, you know, often the  
5 social worker is just not a part of the team,  
6 you know, in your typical primary care  
7 practice.

8 And, so, I think kind of my  
9 takeaway here is to also think about, you  
10 know, the role between medicine and nursing  
11 and social work and physical and occupational  
12 therapy and all of, you know, the other kind  
13 of resources that come into managing, you  
14 know, these patients that involve, you know,  
15 a lot of services outside of your typical  
16 medical diagnosis.

17 MEMBER BAYLIS: I really enjoyed  
18 the process. Particularly, yesterday, when  
19 we brain stormed all the ideas and, then, we  
20 did the multi-voting. And to just see the  
21 degree of agreement that we had was quite  
22 interesting. And, then, being able to

1     assimilate and digest all that today and go  
2     through it and refine it, I think it was a  
3     very good process.

4                     I am proud of the work that we've  
5     accomplished and looking forward to the next  
6     step. And I've enjoyed getting to know the  
7     people in the group. I think that everybody  
8     is bright and has great experience and has a  
9     great deal to contribute. So, it's been a  
10    very good experience. Thank you.

11                    MEMBER CARNAHAN: Yes. I've  
12    really appreciated the group's willingness to  
13    take on the idea of person-centered care and  
14    shared decision making. And I think a lot of  
15    those things are going to be crucial to  
16    whatever recommendations come out of the  
17    group.

18                    But sort of on the flip side of  
19    that there may be some things that we think,  
20    if good shared decision making is done and  
21    good education is done and good clinical care  
22    is provided, they're just not going to

1       happen.

2                       So, if we can also maybe think  
3       about some quality metrics -- I know this a  
4       little late in the game to consider, but --  
5       that are black and white. If there's  
6       anything out there that is truly black and  
7       white, it can be applied, that people should  
8       not get this or they should very rarely get  
9       this, if they have dementia.

10                      If good education is done, then it  
11       won't happen. And, you know, those are  
12       things that are low hanging fruit that could  
13       be implemented.

14                      MEMBER TANGALOS: When I think of  
15       the performance gap, I still come back to the  
16       same issues at hand, that the healthcare team  
17       doesn't grab on, doesn't lock onto the  
18       patients, don't run toward the diagnosis.  
19       They don't rise to the bait. And I think  
20       that is a performance gap.

21                      And, so, that gap and the way we  
22       deliver those services are what I'd like to

1       see as the outcomes.

2                   MEMBER STAPLES:   And I have  
3       already talked about my safety issue but I  
4       can say I'm much more learned for being here  
5       these last couple days with all of you and  
6       it's great to see the compassion in you.

7                   MEMBER GROSSMAN:   I want to thank  
8       everybody.   I've learned a lot over the past  
9       two days, I lot of things I just didn't know  
10      about.   And I think it's really a benefit to  
11      be able to hear everybody's opinions.   And  
12      I've just learned so much.   So, I want to  
13      thank everybody for all that I've learned  
14      over the past couple of days.

15                   I suppose that my parting words  
16      have to do with the assumptions that we make  
17      about what constitutes dementia.   And I think  
18      we make lots of assumptions about what  
19      dementia is and I think that that drives  
20      where we're going.   And I think that lots of  
21      those assumptions -- and when I say  
22      assumptions, I mean assumptions in the

1 community -- are not necessarily accurate.

2 So, I view dementia as a life span  
3 issue, something that begins early on in life  
4 and there are lots of things that we can do  
5 to try to prevent many preventable causes of  
6 dementia. And, when we're stuck with the  
7 assumption that dementia is something that  
8 only occurs in folks who are older, I think  
9 that really does a disservice to us, to our  
10 community, to our population.

11 I think that it's not a fair  
12 assumption to say that dementia is just a  
13 problem of memory. I think that dementia  
14 involves any change in any domain of  
15 cognition, social behavior, language,  
16 interspatial functioning, lots and lots of  
17 domains. And I think it's important for us  
18 to try to remember, it's important for me to  
19 try to remember that dementia isn't just  
20 about memory.

21 It's those kinds of assumptions  
22 that I think are important to push. They're

1 all aspirational. There aren't things that  
2 we can do lots about now. Although there are  
3 some things we can do and I can certainly see  
4 a way forward, although it's a 20 year plan.  
5 It's not even a five year plan.

6 But I think that it's important to  
7 have those goals. It's important for me to  
8 have those goals and maintain those goals and  
9 I see that this Committee is a step on the  
10 way of trying to attain those goals. And,  
11 so, I've really learned a ton over the past  
12 two days about this whole process. And, so,  
13 I want to thank everybody.

14 MEMBER FRISS-FEINBERG: I  
15 appreciate being part of this Committee.  
16 It's been a very thoughtful dialogue and  
17 process and two things come to my mind. I'm  
18 very please that NQF, and it would especially  
19 be true for this group with dementia care as  
20 the focus, is looking at not just the medical  
21 health side but the social care side as well.  
22 And I think for NQF to take the lead on that

1 is critically important.

2 And, secondly, it was very  
3 gratifying for me not to be the only one,  
4 usually I am, talking about the family. And,  
5 again, not a surprise, because we're talking  
6 about dementia care.

7 But for NQF to recommend some  
8 measure of development so that families are  
9 no longer invisible, they are recognized,  
10 their needs are assessed and they are  
11 addressed and supported will be huge. So I  
12 thank you.

13 CO-CHAIR FELDMAN: We caught Joan  
14 in the middle of a biteful.

15 MEMBER TENO: So, I don't have  
16 much of a parting word except, you know,  
17 maybe we should follow the lead of the New  
18 York Times and stop using the words informal  
19 versus informal care givers.

20 MEMBER REUBEN: You know, when we  
21 go around the room like this, I always feel  
22 like I'm back in AA. And I'm Dave Reuben and

1 I am a recovering dementia care provider.  
2 But, in any event, it was a wonderful  
3 experience for me to connect with some old  
4 friends, some very old friends, and meet some  
5 new people and get their perspectives.

6 The take-home messages I would  
7 give is some of the stuff that we came up  
8 with over the past day-and-a-half are going  
9 to be very difficult. They're going to be  
10 very difficult. They challenge paradigms.  
11 NQF and many other organizations work in  
12 really a medical framework.

13 And, in fact, much of what we  
14 talked about today is outside of medical  
15 framework. It's outside of provider-oriented  
16 goals. These are going to be very difficult  
17 paradigms. My take-home message to NQF is  
18 don't do what's easy. Stretch for the stars  
19 and do stuff that's meaningful. You only go  
20 around once in life and you should go for the  
21 best.

22 MEMBER BARTON: I think I should



1     get a prize for having to go after Lynn and  
2     Joan and David here. Okay. So, I would say  
3     do both, easy and hard. And, in the short-  
4     term, I'm just going to punch on things that  
5     have been discussed before.

6                 So, immediately short-term win is  
7     stratification of important measures. And  
8     you've heard a good list here today of what  
9     would be cool ones to start with. And, then,  
10    Joan didn't take the bully pulpit to repeat  
11    her own point. I'm going to repeat it: proxy  
12    respondents for survey measures that are  
13    already in use. I'm banging the table.

14                Not short-term but, in the  
15    intermediate, I'll just remind the group  
16    about what I said before about case finding  
17    for dementia could potentially build on a  
18    risk profile tool and this would be something  
19    that the Committee could recommend further  
20    research on. Just validation of an existing  
21    tool, for example, has been recently  
22    reported.

1                   And, then, the two things that I  
2                   would be so regretful if the Committee did  
3                   not emphasize in the report, one is to get a  
4                   little bit ahead of the terrible silos that  
5                   our healthcare system is stuck in and find a  
6                   way for those shining examples of either  
7                   states that have the demos or dual plans or  
8                   other places, pace programs, other places  
9                   where you could create a measure that other  
10                  people would not even be able to dream of yet  
11                  that had something to do with transitions of  
12                  care and the provision of appropriate  
13                  information from one stage to the next and  
14                  the examination of whether the useful  
15                  information made it, not just did you give  
16                  the patient one.

17                  But, you know, moving towards  
18                  outcomes. I think that would be a good way  
19                  to start because those are place that could  
20                  use the measures and it would be a way to  
21                  inspire the rest of the system to become a  
22                  system that could also report measures like

1       that.

2                       And, then, the second thing to  
3 reach for is in the goal creation and  
4 attainment, which requires that you talk to  
5 people in an open-ended way at first and,  
6 then, potentially, in a more standardized way  
7 about what are the things that they care  
8 about. And, then, you follow up on it and  
9 ask them again.

10                   MEMBER SNOWDEN: Yes. I think I  
11 would like to focus my comments on sort of  
12 the next steps with sort of the example of  
13 how we started. And, if I sort of summed it  
14 up into sort of two main products, there was  
15 a conceptual model.

16                   And the conceptual model had the  
17 advantage of being comprehensive. And we  
18 spent a lot of time. I'm actually not a big  
19 conceptual model person but I was impressed  
20 with how, with each iteration, it actually  
21 did get better.

22                   My concern about what we've done

1 over the last day-and-a-half is that we have  
2 very quickly gone from a very big list to a  
3 very short list. And part of me thinks that  
4 the future work will be to figure out a way  
5 to iteratively think about what we did and  
6 not prematurely close the door to ideas that  
7 may, simply for the lack of time, not have  
8 the same amount of discussion.

9 To me, that's going to be the real  
10 challenge, to have the written part that goes  
11 over the prioritization really do justice to  
12 the breadth of what we did, while also trying  
13 to get to a smaller set of things that are  
14 very well explained.

15 So, to me, the bullet points I  
16 think I sort of get. But just like the model  
17 benefit, I think they're going to need to be  
18 iteratively edited as well.

19 MEMBER HASHMI: So, for me like  
20 Mark said, the whole experience of going  
21 through this measure-development construct  
22 was a new one and I have really loved the

1 process of sort of coming at it from a larger  
2 construct and, then, working towards  
3 measures.

4 The worries that I have is that,  
5 you know, you're developing this work in the  
6 environment of such rapid change in the  
7 external environment. And to not forget that  
8 dollars really do drive behavior, intended  
9 and unintended.

10 And the payment model, the  
11 provider payment model is undergoing rapid  
12 innovation and there is also kinds of, even  
13 now, emerging intended and unintended  
14 behaviors on the providers' side.

15 There's rapid assimilation of a  
16 variety of practices being sold, for example.  
17 So, there's a lot of change going on and we  
18 don't yet know what all it is going to mean.

19 So, to keep that in mind, that,  
20 you know, if you want to put something out  
21 there that considers what's happening in the  
22 external environment.

1                   Then, the last thing is just an  
2                   observation. You know, when we talk about  
3                   team-based care in medical homes and ACOs,  
4                   geriatric care is the ultimate example of  
5                   team-based care because this team extends not  
6                   only in the healthcare setting but it is a  
7                   team consisting of providers in a healthcare  
8                   setting and others both those that are  
9                   recognized, you know, and unpaid providers of  
10                  care.

11                  So, this is the ultimate team.  
12                  So, how do we evaluate the effectiveness of  
13                  team-based care in this larger team constant?

14                  CO-CHAIR FELDMAN: Susan, I feel  
15                  that I should have started with you. We've  
16                  so poorly neglected you. Are you there?

17                  MEMBER COOLEY: I'm here. I don't  
18                  feel neglected at all.

19                  CO-CHAIR FELDMAN: Good. Okay.  
20                  So, now is your time to leave us with your  
21                  parting thoughts. You have the floor.

22                  MEMBER COOLEY: Well, it's never

1 over. I'm sorry but, you know. I feel like  
2 I've been well included and I thank you all  
3 very much. My regret is that, by not being  
4 able to see you visually, I don't know who  
5 was speaking. Some people's voices I know  
6 but even people I know very well sometimes I  
7 can't remember their voices. But many  
8 people's voices I don't know. So, I don't  
9 know who said what.

10 So many things I agreed with and  
11 it's like, yes, yes, yes. I just feel like  
12 you didn't see me nodding my head and  
13 clapping and do other visual responses. But  
14 one thing I do want to say is that it has  
15 been very helpful to me to listen to as well  
16 as participate with this broad group.

17 I've been dealing with these  
18 issues or trying to grapple with them anyway  
19 for some time. And, at least, there is some  
20 validation that it's not just me not being  
21 able to solve all these problems. But, you  
22 know, there are no easy answers.

1                   These are many, many needs, of  
2                   which I knew, some new things that I heard at  
3                   this meeting. There are very complicated  
4                   measurement issues and it's just not an easy  
5                   area. So, just like everybody else, I have  
6                   my favorites of what I think are top  
7                   priorities or ones that are more urgent needs  
8                   that others flow from. Others have their  
9                   favorite lists.

10                  But the conceptual model to me  
11                  also we very helpful going through that  
12                  experience as a overarching guide. So, I  
13                  appreciated having the conceptual model as  
14                  something to go back to, after we were  
15                  deconstructed, as I would have said, over the  
16                  past couple of days.

17                  And, then, I will just also say  
18                  that many times I feel I am overwhelmed by  
19                  this because there are so many needs, such  
20                  pressing issues and it can feel overwhelming.  
21                  I know I feel overwhelmed many times. And  
22                  one of my bosses, in a different but related



1 context, told me don't lose heart. So, I  
2 wrote that down. I have that in front of me  
3 among other things on my computer. Don't  
4 lose heart because I do believe, at least I  
5 hope, that we can make progress and we can  
6 help improve lives. We can help people and  
7 that's a bottom line.

8 So, I'm trying not to lose heart  
9 and I've found a lot of encouragement through  
10 the rest of you at this meeting.

11 CO-CHAIR FELDMAN: Thank you,  
12 Susan. Matthew, you haven't --

13 MEMBER JANICKI: I'm dealing with  
14 a flight cancellation, so my mind is trying  
15 to get home. Could I pass for a minute?

16 CO-CHAIR FELDMAN: Sophie, do you  
17 want to?

18 MS. OKOLO: I just want to say  
19 thank you for all your comments and ideas. I  
20 have really learned a lot the past two days.  
21 And, normally, one thing will be I think,  
22 until we become a pro-aging society, then

1       these things can be works in the well. So,  
2       that's my only think. Thank you.

3                   CO-CHAIR FELDMAN: So, I guess  
4       it's my turn to say a few words. There are  
5       two words that my friends and colleagues  
6       would never use to describe me. One is  
7       humble and the other is quiet.

8                   So, I must say that I really feel  
9       great humility at being in this group. You  
10      know, the amount of knowledge, expertise,  
11      wisdom and commitment to this whole area is  
12      just so great. I've really been humbled and  
13      I really thank you.

14                  You've contributed enormously to  
15      this meeting but, also, I really, as I think  
16      I said at the beginning, have been, you know,  
17      genuinely impressed at people's willingness  
18      to do extra tasks and to do things by email  
19      and so forth. That's not always, by any  
20      means, typical of a group like this. And,  
21      so, that's number one.

22                  I also wanted to thank my co-

1 chair, Eleanor, from whom I've also learned a  
2 huge amount and who was just amazing. And to  
3 thank the staff, Karen and Juliet and Taylor.  
4 You get a sense of all the lot of preparation  
5 that they've done for this. And, if you  
6 could have seen. The annotated agenda is  
7 about ten pages long and there is just not a  
8 detail left.

9 And I think, certainly for myself  
10 and I probably speak for Eleanor, you know,  
11 part of the reason that this meeting has gone  
12 so well has to do with the amount of care and  
13 preparation on the part of the staff that  
14 went into this. So, I'm really grateful for  
15 that.

16 I do have a couple of parting  
17 shots. One is kind of this lingering  
18 concern. There's a lot of research on care  
19 coordination and care management and there's,  
20 you know, in one of the early IOM reports  
21 that said, you know, if everybody's  
22 accountable, nobody's accountable and that

1 the person, they used the term "patient," but  
2 if the person and the family don't have sort  
3 of a person and a phone number who is the  
4 single accountable person, that this doesn't  
5 work very well.

6 And, so, I deeply believe and we  
7 have taken the approach about recommending  
8 performance measures at all levels and across  
9 the system. I'm not sure that we've fully  
10 addressed this issue of when a person  
11 encounters the health and social service  
12 system, is there an accountable person. I  
13 don't know how we do that.

14 But I mean we talked a lot about  
15 linkages and stuff but that's something  
16 that's kind of lingering in my mind.  
17 Secondly and granted I do speak from the  
18 point of view of somebody who's sat in a  
19 large and sophisticated community based  
20 healthcare organization over the last almost  
21 20 years and, also, as a lay person in terms  
22 of my own experience, but I want to be

1 cautious that, in this report, that, in our  
2 effort to include community-based  
3 organizations and families, that we not  
4 absolve the medical part of the system from  
5 its responsibilities here.

6 And it goes back to what, you  
7 know, Eric had to say. It's very easy when  
8 the person and the family are in denial and  
9 it takes a lot of time and it's very complex  
10 to just treat the immediate, whatever the  
11 immediate thing is not to delve further.  
12 And, so, I think we've been very  
13 conscientious and genuine in talking about  
14 the role of the community-based organizations  
15 and so forth.

16 But, in doing so, I want to be  
17 sure that we don't absolve the medical part  
18 of the system here from its responsibilities  
19 and recognize that very often families who  
20 are in denial, even when they contact the  
21 Alzheimer's Association, they're looking for  
22 a physician.

1                   And, you know, most often people  
2                   are going to their primary care physician  
3                   with these amorphous unnamed things that are  
4                   bothering them and they're looking to their  
5                   primary care physician for some advice and  
6                   recommendation. And, so, again, I think it's  
7                   very important that we emphasize the role of  
8                   the person's point of contact with the  
9                   healthcare system.

10                   So, you see, I said I was feeling  
11                   humble but I definitely was not quiet. You  
12                   know? So, thank you all. Karen, you wanted  
13                   to speak and do we do our public comments  
14                   next? How do we want to do that?

15                   MS. FELDMAN: Hi, operator.  
16                   Kathy, can you please open up the lines for  
17                   public comment?

18                   OPERATOR: At this time, if you  
19                   have a public comment, please press star one  
20                   on your telephone keypad. We'll pause just a  
21                   moment to compile the roster.

22                   MS. FELDMAN: We'd also like to

1       invite any of the public attendees to offer  
2       comment at this time.

3               OPERATOR: Again, for comments,  
4       please press star one.

5               MS. JOHNSON: I'm going to give  
6       D.E.B. a chance. We've heard from her a  
7       couple of times. So, just in case you want  
8       to have some parting words.

9               MS. POTTER: I just wanted to  
10      thank you all for your thoughts. It's really  
11      appreciated. As someone who comes from long-  
12      term care, it's really nice to hear long-term  
13      care and healthcare be talked about at the  
14      same meeting and community-based supports and  
15      social services.

16              I want to thank you all for your  
17      aspirational thinking because, in order to  
18      move the system, we have to be aspirational.  
19      That's my personal opinion. Do not attribute  
20      it to any organization I work with.

21              (Laughter)

22              But I just wanted to thank you and

1 I wanted to thank Penny and Eleanor and the  
2 NQF staff for all their help. And you should  
3 all give yourself and everyone else an  
4 applause, including Susan. So, thank you.

5 (Applause)

6 MS. JOHNSON: Okay. We're going  
7 to end up with just a few final next steps.  
8 Since everybody else got to say thank you for  
9 everything, I'd really appreciate, I know you  
10 guys have given us a lot of feedback, a lot  
11 of help. My co-chairs have been fantastic.  
12 I haven't had nightmares about the meeting  
13 because I knew we'd be in good hands.

14 And D.E.B. is a great GTL. You  
15 wouldn't imagine the number of emails with  
16 information that she sends me. Almost daily  
17 I get something from D.E.B. and I really  
18 appreciate it.

19 MS. POTTER: Please, not daily.

20 MS. JOHNSON: Well, maybe it just  
21 seems like daily sometimes because I can't  
22 keep up with everything. But I've learned a



1 lot from you and I really appreciate that.  
2 So, it's just great to work with people who  
3 care and are willing to share with others.

4 So, with that, let's talk about  
5 next steps and what we plan to do next.

6 MS. FELDMAN: So, obviously, after  
7 this meeting, we are going to be synthesizing  
8 all of these deliberations. We'll be  
9 drafting a meeting summary over the next  
10 week, which is due to HHS within seven  
11 business days. So, that'll be our first task  
12 at hand. We'll be sure to circulate that to  
13 the group.

14 And, then, after that, we are  
15 going to get into drafting the report. And  
16 we'll be sure to involve you and we'll be  
17 following up. We've identified at least two  
18 subgroups of the Committee that we'll be  
19 working with during the next summer months.  
20 And, just as this slide indicates, the draft  
21 report is due to HHS on August 15th.

22 There will be a public comment

1 period on that draft report. It's a three-  
2 week public comment period between late  
3 August and early September. There will also  
4 be a public webinar. But the final report  
5 due to HHS on October 15th.

6 MS. JOHNSON: And let me close  
7 with just a couple of things. We've  
8 mentioned at least twice I think in these  
9 meetings and even before that that there are  
10 the other task five gaps projects that are  
11 going on. The ones that are particularly  
12 salient to us are the workforce one, the care  
13 coordination one and the person and family  
14 centered care and outcomes task.

15 And those reports, they had  
16 meetings similar to this. Those reports are  
17 going out soon for comment. Several of you,  
18 throughout the meeting, have made comments  
19 that make me think you might be particularly  
20 interested in one or two of those. So, if  
21 you have the time and the inclination, it  
22 would great if you would take a peek at

1       those.

2                       And, if you have any comments,  
3       particularly if you have it in terms of, you  
4       know, how the dementia might be folded in,  
5       so, again, we're learning from them and we  
6       did that specifically for this project. But,  
7       if you have any comments for them about how  
8       workforce and dementia should go in, so that  
9       they can enfold that into their work, that  
10      would be a nice feedback loop.

11                      So, we're not going to ask you  
12      formally to do that and certainly not as a  
13      group to do that. But, if any of you  
14      personally have the inclination, that would  
15      be great.

16                      MS. FELDMAN: And I can circulate  
17      the link for that.

18                      MS. JOHNSON: Well, we have an  
19      half hour extra time. I don't see anybody  
20      sad about that. So, safe travels everyone.

21                      (Whereupon, the above-entitled  
22      matter was concluded at 1:27 p.m.)

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In the matter of: Alzheimer's Disease and  
Related Dementias Committee

Before: NQF

Date: 06-03-14

Place: Washington, DC

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