

NATIONAL QUALITY FORUM

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ALZHEIMER'S DISEASE AND
RELATED DEMENTIAS COMMITTEE

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MONDAY
JUNE 2, 2014

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The Committee met at the National Quality Forum, 9th Floor Conference Room, 1030 15th Street, N.W., Washington, D.C., at 9:30 a.m., Penny Feldman and Eleanor Perfetto, Co-Chairs, presiding.

PRESENT:

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

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

NQF STAFF:

JULIET FELDMAN
KAREN JOHNSON
ELISA MUNTHALI
TAYLOR MYERS
WENDY PRINS

ALSO PRESENT:

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

* present by teleconference

A-G-E-N-D-A

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

2 9:32 a.m.

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

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

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

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

1 the content expert for this one.

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

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

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

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

20 This is an incredible group that's
21 been so participatory in response to all the
22 emails that go out. And we've just done so

1 much in advance and made so much progress that
2 I'm really looking forward to a very
3 productive two days.

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

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

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

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

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

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

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

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

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

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

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

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

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

22 MEMBER TANGALOS: I'll try again.

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

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

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

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

18 MEMBER ZWEIG: Hi, my name is Yael
19 Zweig. I'm a nurse practitioner at the New
20 York University School of Medicine and I see
21 patients clinically in our memory-specific
22 department, the Pearl Barlow Center. And I'm

1 a nurse representative nominated by the
2 American Nurses Association.

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

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

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

21 MS. MYERS: Good morning, Taylor
22 Myers, administrative assistant. And I'm

1 supporting this project as well as two others
2 here at NQF.

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

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

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

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

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

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

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

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

22 And you know, I don't even work in

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

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

15 MEMBER SNOWDEN: Good morning, I'm
16 Mark Snowden with the University of Washington
17 in Seattle. There I practice clinically in a
18 geriatric medicine primary care program where
19 I'm the in-house geriatric psychiatrist. And
20 then I work in nursing homes. I do research
21 with the Health Promotion Research Center and
22 the Healthy Aging Research Network which is

1 sponsored by the CDC. And my current dementia
2 work focuses on dementia and comorbid chronic
3 conditions.

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

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

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

21 I also lead a grant to develop
22 patient-centered goal-attainment scaling

1 measures for patients with Alzheimer's disease
2 and their caregivers. And we're developing
3 new outcome measures hopefully.

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

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

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

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

1 our trade organization.

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

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

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

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

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

22 I am a clinical psychologist with a

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

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

16 CO-CHAIR PERFETTO: Thank you, Susan.
17 So I'm going to task everyone in the room with
18 every once in awhile reminding Penny and
19 myself that Susan is on the phone and that we
20 need to stop and see if she has any questions
21 or any comments. Because it's sometimes so
22 difficult when someone's on the phone for them

1 to get a word in. So we all have to be
2 mindful that Susan is there.

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

5 (Laughter)

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

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

11 (Laughter)

12 MEMBER COOLEY: Okay. Thanks, I
13 appreciate that.

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

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

1 all about.

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

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

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

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

21 And then lastly, where we really want
22 to end up tomorrow is with the prioritization

1 of opportunities for performance measurement
2 for people with dementia and their family
3 caregivers.

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

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

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

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

22 And again, I don't know how well you

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

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

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

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

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

22 And then an opportunity to discuss

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

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

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

22 CO-CHAIR PERFETTO: So, just some

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

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

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

14 We're going to have an opportunity
15 for the participating audience to have some
16 comment also. We're going to try to work to
17 consensus. We're going to make sure that we
18 meet the objectives that our NQF colleagues
19 have worked so hard to get us to the goal.
20 And they have to walk out of here tomorrow
21 feeling like they've got what they've needed
22 to take the project to the next step. And

1 we're going to try to do our best to stay on
2 time.

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

6 It grew out of the National
7 Alzheimer's Project Act which was passed in
8 2011. The National Plan actually calls for
9 the development of quality measures and it's
10 why we're all here today.

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

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

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

1 Coordination, previously with CMS and ADMII.

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

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

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

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

22 And this task actually was purposely

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

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

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

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

21 As you are also well aware we have
22 developed or refined a conceptual measurement

1 framework that we term as the bubble diagram.

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

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

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

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

22 So very briefly, we just wanted to

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

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

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

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

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

1 National Quality Strategy.

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

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

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

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

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

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

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

17 So related to care coordination NQF
18 has done quite a bit of work in this area. In
19 2006 there was a committee that identified
20 five domains essential for future performance
21 measurement of care coordination: healthcare
22 home, proactive plan of care and follow-up

1 communication, information systems and
2 transitions and hand-offs.

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

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

10 There was an endorsement project in
11 2012 that endorsed 12 endorsed maintenance
12 measures.

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

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

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

21 And then lastly, just some other
22 related NQF projects that are related to this

1 topic is that the Measure Applications
2 Partnership has a dual eligible beneficiaries
3 workgroup as well as a post-acute care long-
4 term care workgroup.

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

11 And then lastly, the neurology
12 endorsement maintenance project. That was in
13 2013. And there were several dementia-
14 specific measures that were reviewed during
15 that project. So that's why we call that out
16 here.

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

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

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

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

21 MS. JOHNSON: Thank you so much. So,
22 from Juliet's summary you know that there's a

1 lot going on at NQF as well as other places.
2 I know a lot of you are involved in other
3 kinds of projects that are thinking about
4 dementia.

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

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

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

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

22 We're using these microphones and we

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

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

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

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

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

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

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

20 So when we talk about a measure
21 generally we are talking about measures of
22 providers or organizations. So, you can have

1 patient-level measures, or measures such as a
2 blood pressure, or lab score, or information
3 from a survey like the CAHPS or something like
4 that. Those are patient-level measures.

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

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

19 And that provider might be an
20 individual clinician, it could be a facility,
21 a home care agency, an ACO, all kinds of
22 different levels of aggregation there. So, I

1 wanted to make sure that we were all
2 comfortable with the term "measure."

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

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

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

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

22 There are lots of different types of

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

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

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

20 And we also have intermediate
21 clinical outcome measures. Those are things
22 like blood pressure rates, percentage of

1 patients that are in controlled HbA1c, for
2 example. Those kind of things are intermediate
3 clinical outcomes.

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

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

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

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

21 There are some other kind of fancier
22 kinds of measures. We talk about composite

1 measures. Now, a composite measure is really
2 just a combination of other types of measures.
3 And it could be a combination of outcomes, or
4 a combination of process measures, or a
5 combination of any of the above in any kind of
6 way.

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

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

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

22 But we do have criteria that we use

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

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

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

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

21 Process measures, structural
22 measures, some of those -- can you go to the

1 next slide? I think we show this a little bit
2 in the next slide. Yes.

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

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

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

19 So, if you're thinking about
20 assessing somebody and then figuring out a
21 diagnosis, and then finding a treatment, and
22 applying that treatment, and then seeing if

1 the outcome is what you are hoping based on
2 that treatment, there's places for measurement
3 in all those different steps of the care
4 process.

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

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

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

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

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

22 MS. JOHNSON: Thank you, Susan.

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

4 MEMBER COOLEY: Okay. Sorry to
5 interrupt.

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

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

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

19 So basically the PRO would be a
20 patient-reported outcome, for example,
21 depression. And you usually would use some
22 kind of instrument or scale, something like

1 that to figure out if somebody has symptoms of
2 depression. So that would be the PROM, the
3 patient-reported outcome measure.

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

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

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

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

20 You could think about facility-level
21 measures. And again, that would be, it could
22 be a hospital, it could be a home health

1 agency, a hospice agency, something like that.

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

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

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

22 I mentioned very briefly that NQF

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

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

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

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

20 Scientific acceptability. What we
21 want is to make valid conclusions about
22 quality so we need measurement that gives us

1 both reliable and valid results.

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

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

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

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

1 our knowledge.

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

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

1 NQF tries to do.

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

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

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

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

20 So one of the things that we have to
21 talk about at some point later today and
22 tomorrow is when you put forward measures,

1 your prioritized list, we are not necessarily
2 saying that things have to be ready for NQF
3 endorsement. Because maybe we're not quite
4 there yet in terms of the science. And that's
5 okay.

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

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

18 When we finish this little soliloquy
19 from Elisa and I we'll open up the floor and
20 we'll start talking about the challenges that
21 we're going to be facing with measurement.
22 And some of the things that we want to get on

1 the table before we delve into the real meat
2 of our day. So, Elisa.

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

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

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

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

22 Specifically, we're focusing on the

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

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

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

19 And they wanted to know whether those
20 criteria were applicable to population health
21 measures. And by and large they decided that,
22 yes, these should be applicable to population

1 health measures, but we may need to change
2 some of the clinical terminology and
3 nomenclature included in there.

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

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

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

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

21

22 So, the committee landed on two very

1 important definitions that I did want to share
2 with you.

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

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

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

19 As I mentioned before, there were
20 many things that Steve and Dawn went out there
21 to look for us as we began this foundational
22 work. And one of them was really giving us

1 guidance on how to measure and assess
2 population health, the determinants of health
3 and improvement activities.

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

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

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

20 So, in the end we had a two-phased
21 project as part of this inaugural project and
22 we endorsed 19 clinical preventative services

1 measures. So those speak to the National
2 Quality Strategy's emphasis on the clinical
3 preventative services. And it included
4 immunization measures as well.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

21 And so we did extensive technical
22 assistance and worked with the developer to

1 change the measure using another survey tool
2 that could be assessed at the state level.
3 And that was the BRFSS, Behavior Risk Factor
4 Surveillance Survey. And so with that they
5 felt a lot more comfortable with this measure
6 that was able to drill up and drill down.

7 And I think that's it for me.

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

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

21 So, there's a lot of measurement
22 challenges, right, about measuring for quality

1 of care for the dementia population. And
2 we've put a few of these on some slides. And
3 I'll just go through them very quickly.

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

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

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

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

20 As I mentioned before NQF is really
21 interested in measurement that has a strong
22 evidence base. But we may not have a strong

1 evidence base for things like prevention and
2 treatment and screening, things like that.
3 Maybe the science hasn't quite caught up to us
4 yet. So that's another challenge as we think
5 about prioritizing things.

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

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

15 So, as we go through the next about
16 20 minutes or so what I want to do is open up
17 the floor for you guys to talk about other
18 challenges that we may want to get on the
19 table as well as considerations for
20 prioritization.

21 So, what would be really great is if
22 we had a list of things for you to use to

1 prioritize, right? We don't quite have that
2 list. But things that we might be thinking of
3 are accountability versus QI, the types of
4 measures. By that I mean the structural
5 process outcome. The levels of analysis, et
6 cetera.

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

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

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

19 We have certain high-risk populations
20 that we need to be sure that we don't leave
21 out. There's lots of creative and novel
22 approaches for doing measurement. We talked

1 about, real quickly, the PRO-PMs and the
2 composite measures but I'm sure there are
3 others.

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

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

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

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

21 I was struck by the fact that we know
22 that person- and family-centered care is a

1 priority for the National Quality Forum. And
2 yet within the slides even sometimes within
3 some of the columns the word "person" was used
4 and then "patient" was used.

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

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

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

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

20 She's thrown some out here that are
21 on the slides that she just reviewed. But is
22 there anything that we're missing, or anything

1 that's here but needs to be elaborated on in
2 any fashion?

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

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

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

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

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

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

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

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

21 CO-CHAIR PERFETTO: Karen, could you
22 comment on that? Has NQF dealt with that

1 before in the past for other areas that it's
2 done work on where there's been any thought to
3 an individualized measurement approach?

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

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

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

17 Now, I think, and Eleanor, you could
18 talk to this. For -- when NQF did some work
19 and Eleanor was on the panel on the patient-
20 reported outcomes, one of the first questions
21 in that pathway of going was is this, this
22 thing that you're thinking about measuring, is

1 that actually important to the patient? So,
2 from that perspective I think it is.

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

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

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

22 And so the idea is it began with the

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

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

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

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

17 But it seems to me that it leads back
18 to some very complicated aggregation of
19 individual process and outcome goals where
20 you, you know, you sort of identify what the
21 person's preferred outcome is through a
22 process and then you link it up to the desired

1 outcome. And then you try to aggregate it up.

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

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

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

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

21 So I think it's a huge issue. And
22 maybe one of our recommendations of some kind

1 going forward could be to direct more work in
2 this area. It seems rather inadequate to what
3 we're grappling with.

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

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

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

18 But the concept of patients with
19 dementia being treated not just in a medical
20 setting but also in a social care setting.
21 And so how to integrate these outcome
22 measures, how to think about if we are

1 thinking about quality indicators more for the
2 medical system which ones can we really hold
3 the medical care system accountable for? How
4 should they be responsible?

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

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

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

19 MEMBER MASLOW: I don't want to take
20 away from what Chris said, but thinking about
21 what Dave raised, it seems to me that for
22 people with dementia something that is

1 generally not happening now and would be a big
2 plus is a structured care planning process.

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

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

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

17 MS. JOHNSON: Subdomains go across.

18 MEMBER MASLOW: Subdomains.

19 MS. JOHNSON: Yes.

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

1 there's not enough attention to it.

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

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

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

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

21 MS. JOHNSON: And just to make sure,
22 you probably saw it in some of those pre-

1 meeting materials that we made available in
2 some of the other task 5 work we do have a
3 person- and family-centered care group. And
4 they've grappled with this. And they've made
5 some recommendations.

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

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

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

18 CO-CHAIR PERFETTO: Cyndy?

19 MEMBER CORDELL: I just want to say
20 that one thing that should be a bullet is this
21 is a disease that has no treatment to stop its
22 progression or cure it, and that's one of our

1 issues on why it's so difficult to get a
2 typical outcome measure that we're used to
3 seeing.

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

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

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

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

1 clinical condition or a social condition.

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

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

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

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

19 But also as looking at the documents
20 you sent up one of the things that struck me
21 is that there's not a foundational
22 differentiation of what Alzheimer's and

1 related dementias is in relation to other
2 public health medical issues.

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

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

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

21 I think maybe a starting point is
22 really to say, okay, what is it about dementia

1 and its related conditions that really
2 differentiates it somewhat from other factors
3 and then how do we address those measurements.

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

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

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

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

22 And the example I'll give you is the

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

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

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

22 Well, that means when you start

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

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

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

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

22 So I wouldn't underestimate that

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

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

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

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

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

22 MS. JOHNSON: Okay, I think we got

1 some great input. So this is great.

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

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

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

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

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

1 11:17 a.m.)

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

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

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

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

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

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

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

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

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

22 MS. JOHNSON: This is what we came up

1 with.

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

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

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

1 through this.

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

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

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

21 MEMBER BAYLIS: When you say it, it
22 makes sense to me but I don't see it in the

1 model, that one part is -- oh, that's so
2 light. Okay, caregiver, thank you.

3 (Laughter)

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

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

9 MEMBER BAYLIS: Okay.

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

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

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

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

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

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

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

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

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

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

6 CO-CHAIR PERFETTO: Very good. Lynn?

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

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

16 CO-CHAIR PERFETTO: Maybe all of
17 them.

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

22 But we'll also keep in mind that

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

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

9 CO-CHAIR PERFETTO: Yes, yes, okay.

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

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

21 But the second point really has more
22 to do with maybe family counseling. You're

1 dealing with a course of a disease that
2 oftentimes may have people raise issues in
3 their own minds, other family members, whether
4 that's going to be in their genetic structure
5 or not.

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

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

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

22 But then in the person with dementia

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

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

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

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

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

1 (Off mic comment.)

2 MS. JOHNSON: Can you repeat that?

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

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

11 MEMBER REUBEN: I think those are
12 both great ideas.

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

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

1 for the caregiver and for the person.

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

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

6 (Laughter)

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

11 CO-CHAIR PERFETTO: Okay.

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

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

21 What I'm thinking about here is that
22 families are quite concerned about familial

1 history and whether there are lots of folks
2 that are involved.

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

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

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

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

19 MEMBER MASLOW: If the two were
20 below, which I think is a good idea, the
21 person and the family, I wish there was
22 something here that would trigger this

1 question about who is the answerer for the
2 quality measure.

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

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

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

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

19 CO-CHAIR PERFETTO: Got it. Got it.

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

22 It did strike me, you know, in light

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

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

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

19

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

22 MEMBER SNOWDEN: I think what the

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

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

8 MEMBER SNOWDEN: Right.

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

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

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

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

22 MEMBER JANICKI: You can take mild

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

4 CO-CHAIR PERFETTO: Right.

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

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

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

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

20 CO-CHAIR PERFETTO: Right. We'll
21 take a few more comments and then we'll move
22 onto the next topic. And I don't know what

1 order that happened in down there. Joan?

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

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

10 (Laughter)

11 MEMBER TENO: But it would be so
12 cool.

13 CO-CHAIR PERFETTO: Agreed. Lynn?

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

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

1 think of as end of life.

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

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

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

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

1 depending on lots of different factors.

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

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

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

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

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

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

22 MEMBER KAHLE-WROBLESKI: So, I am

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

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

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

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

22 Prior to entry into the rehab center

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

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

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

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

21 Do you want me to read the part of
22 the gaps? I mean, for me there were multiple

1 gaps in the quality of care for this
2 gentleman.

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

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

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

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

21 So the next one that we're going to
22 go onto is under the category of care,

1 treatment and support for persons with
2 dementia. And Dr. Tangalos is going to cover
3 that one next.

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

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

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

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

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

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

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

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

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

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

1 center.

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

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

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

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

22 She was previously hospitalized and

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

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

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

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

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

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

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

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

18 CO-CHAIR PERFETTO: So, we've had
19 some vignettes that have been provided based
20 on some different scenarios. One being the
21 initial symptom awareness and initial
22 detection. Another being care, treatment and

1 support for persons with dementia in those two
2 scenarios that we just heard.

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

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

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

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

19 And similarly, lack of a standardized
20 person communicating the diagnosis, or helping
21 family members come along is also again a
22 failure of the healthcare system in terms of

1 knowledge possibly.

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

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

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

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

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

22 So, folks with Parkinson's spectrum

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

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

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

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

21 MEMBER KAHLE-WROBLESKI: Well, so I
22 would add to the lack of assessment, and I

1 think someone else mentioned this, it's that
2 detection issue.

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

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

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

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

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

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

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

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

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

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

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

22 MEMBER REUBEN: To build on some work

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

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

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

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

20 And so this whole idea of after
21 somebody has the dementia it's counseling,
22 it's support services, it's support groups,

1 it's caregiver services, all this stuff that
2 drops off the face of the universe.

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

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

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

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

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

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

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

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

20 So by the time we got into Manhattan
21 my mom was in the emergency room. And because
22 again there were no obvious signs of injury or

1 stroke it was about six hours till she was
2 seen by the physician. My husband and I were
3 there.

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

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

20 CO-CHAIR PERFETTO: Katie.

21 MEMBER MASLOW: I'm just struck by
22 how complicated this is. So we heard three

1 vignettes and now yours also, Penny. And
2 extremely complex.

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

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

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

19 I think that the pulling apart of
20 trying to find these measures uses that
21 overarching concept. This is very important
22 for the care of coexisting conditions. It's

1 likely to be messy. It's likely -- you're
2 looking at a lot of different providers in the
3 community, a lot of different people in the
4 healthcare setting.

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

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

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

22 MEMBER COOLEY: Susan Cooley. That's

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

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

18 Maya Angelou, I don't know actually
19 what happened to her. Not Maya Angelou, Ann
20 Davis, the Brady Bunch person who apparently
21 fell and had subdural hematoma, didn't wake
22 up. I mean, I don't know the circumstances

1 but these things happen. People fall.
2 Something could happen. Some families will
3 want to have everything done. Others will
4 not.

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

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

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

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

1 Alzheimer's disease and dementia.

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

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

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

17 It would be good to have the earliest
18 appointment in the day because he's freshest
19 in the morning and quiet is good, not a lot of
20 people in the waiting room. I don't have
21 anything open at that hour. Nothing, nothing.
22 I can put you on at 1 o'clock after lunch and

1 things are pretty quiet then because we're
2 restarting. So I said okay, 1 o'clock.

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

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

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

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

22 And finally we got seen after --

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

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

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

21 And it was kind of like I could see
22 the light bulb go off where he was like oh, I

1 get what you mean. Yes, we could give him
2 repeated cortisone injections, couldn't we.
3 Yes.

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

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

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

18 I believe, Matt, you are next.

19 MEMBER JANICKI: I don't know if you
20 had a chance to read over the one I sent you,
21 but from the area of intellectual disabilities
22 this situation of the woman that we wrote

1 about is fairly typical.

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

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

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

21 Subsequently she became much more
22 agitated and aggressive and her husband

1 couldn't cope with her. She had other
2 problems. She had lost her job obviously at
3 this point. She was becoming much more
4 physically dysfunctional as well.

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

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

20 The issue that this brings up is a
21 number of other factors. The care then fell
22 upon the mother because the organization that

1 actually took her, the daughter in to provide
2 her with some services after the job fell
3 apart and everything else was overwhelmed by
4 the dementia symptoms. They weren't prepared
5 to deal with someone at that level.

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

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

21 She then took on the prime
22 responsibility for caring at home and was in

1 contact with another organization who was much
2 more sympathetic to providing care for
3 dementia. So that woman, the daughter is now
4 in care of the other organization in the day
5 program but still lives at home.

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

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

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

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

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

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

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

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

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

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

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

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

19 And let me just say that -- I mean, I
20 know we're getting ahead of ourselves here,
21 but put on the parking lot for later is to
22 think about a quality indicator of a

1 healthcare system and whether they have
2 accommodations for people with dementia.
3 Which would be a big improvement and something
4 that could be measured. It's actually a
5 structural measure. Maybe a process measure.

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

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

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

21 Because the health system is designed
22 to provide healthcare. It's not designed to

1 accommodate personal wishes.

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

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

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

20 And then also the person-centered
21 care.

22 Under the end of life and bereavement

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

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

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

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

22 And there's a lot of work by the

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

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

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

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

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

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

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

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

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

22 And she really on her own kind of sat

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

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

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

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

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

22 And I also wanted to kind of

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

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

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

1 although we lived -- my sisters and I lived at
2 a distance.

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

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

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

22 The social worker said the same

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

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

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

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

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

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

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

19 "Counseling them involved validating
20 everything they were doing and discussing its
21 benefit given the fact that it focused on
22 engaging the mother's senses. They thought

1 reading may be frustrating for the mother
2 because she could no longer comprehend the
3 text, but we talked about the value of the
4 tone, flow and intent.

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

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

19 "I remember this case so well because
20 the relief that the couple expressed at being
21 told that they were doing the right things and
22 that they could still offer so much even in

1 the late stage was palpable. It clearly
2 alleviated some of the caregiver guilt they
3 were feeling."

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

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

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

20 MEMBER BARTON: Thanks. I just
21 wanted to mention that, Lynn, what you were
22 talking about made me think about the fact

1 that insurance plays a role here. And many
2 nursing homes I think are reluctant to call in
3 hospice because of the way the financing
4 works. And I suspect that this is more than
5 this group wants to take up.

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

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

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

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

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

7 The next door neighbor fed this
8 patient with dysphagia a peanut butter and
9 jelly sandwich. We ended up having to call
10 911, send the patient to the ER and required
11 actually ICU stay with bronchoscopy to take
12 out one peanut butter and jelly sandwich.

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

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

21 MEMBER JANICKI: The vignettes all
22 kind of point to the same problems and that's

1 the issues of accurate diagnosis oftentimes.

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

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

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

17 The nice thing about what happens in
18 our field in intellectual disabilities is the
19 states generally have lifetime kind of
20 supports that they offer to people with
21 disabilities. And it's a question of
22 transitioning into the right type of support

1 that's still funded and still available
2 because of dementia.

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

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

19 And so we've been sort of promoting
20 the notion of developing community-based
21 services, dementia care services. So those
22 are really the issues I think in terms of the

1 diagnostic challenges we have to find the
2 right diagnosticians who understand the
3 discrimination of the condition.

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

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

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

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

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

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

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

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

18 But these are two different cultures.
19 They're completely different cultures. And
20 it's truly an obstacle to providing
21 comprehensive care that bridges both health
22 needs, medical needs and social needs. This

1 is a paradigm disease where both needs are
2 equally important.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

20 And so if someone is dementia-
21 sensitive and dementia-capable it can be a
22 very easy experience for the patient and the

1 caregiver and the facility where the care is
2 being provided.

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

8 CO-CHAIR FELDMAN: And then the
9 authority system.

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

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

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

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

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

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

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

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

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

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

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

17 MEMBER KAHLE-WROBLESKI: So we've
18 done some research looking at -- we're not
19 sure that they're caregivers, but we've looked
20 at spousal dyads in Medicare and we do see
21 that the spouse of someone that has
22 Alzheimer's disease does have significantly

1 higher costs than their age-matched controls.
2 So we've seen that there's something there,
3 right?

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

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

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

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

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

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

21 So I think there's also when we talk
22 about caregiver burden there are caregivers

1 out there that the actual caregiver, other
2 people have to get involved because sometimes
3 that caregiver doesn't want to.

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

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

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

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

22 But I think these are some of the

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

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

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

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

21 It's not these generic things, it's
22 kind of where do I find a Farsi-speaking

1 support group. Where do I find that?

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

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

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

21 And so we talked about denial of
22 patients and families. We also have denial

1 within the healthcare system as well. We have
2 a tremendous amount of -- and again, it goes
3 back to my vignette. I mean why wasn't the
4 ground paved better for me to step into the
5 situation?

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

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

16 But now that we have a legitimate
17 diagnosis of Mild Cognitive Impairment, in
18 capital letters, we have physicians and
19 practitioners all over the place that diagnose
20 mild cognitive impairment in small letters
21 when the patient really has a far advanced
22 disease. And it's a misuse of terminology, in

1 my estimation, intentionally so that you can
2 just get out of that situation and not address
3 it further.

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

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

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

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

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

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

20 But I don't know that this is a
21 quality indicator, but it might be part of a
22 report that talked about some of the

1 challenges and barriers in the healthcare
2 system of denying the importance of the
3 caregiver in these situations.

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

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

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

20 CO-CHAIR PERFETTO: Well, I want to
21 thank everyone who provided the vignettes.
22 That was really very nice of you to put the

1 information forward, especially the personal
2 information. I can appreciate that.

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

9 Karen, do you have a comment?

10 MS. JOHNSON: Juliet.

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

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

21 And there are no public comments on
22 the phone lines.

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

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

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

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

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

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

1 to be doing?

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

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

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

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

22 MS. JOHNSON: Yes.

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

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

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

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

16 MEMBER COOLEY: Great.

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

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

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

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

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

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

19 And I said, David, this sounds really
20 great. I didn't get it all down when we were
21 taking notes. Could you scribble it on the
22 back of a napkin and send it to us? And he

1 actually did and that was the genesis, David's
2 napkin, of this grid.

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

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

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

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

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

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

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

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

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

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

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

1 prevention subdomain.

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

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

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

21 But for example, when we talk about
22 doing assessment for the signs and symptoms of

1 dementia we didn't actually go in and put down
2 all the different signs and symptoms of
3 dementia. Because that is the job of the
4 measure developer down the road.

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

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

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

19 And what I suggest that you do is use
20 some time to discuss the various concepts that
21 might fit into those two domains. And then
22 spend a little bit of time using dots, it's

1 your favorite dot exercise. I'm sure you guys
2 have done that a lot of times.

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

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

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

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

22 I'm a very visual person so on the

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

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

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

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

21 One more thing to talk about real
22 quickly. What we're trying to do is

1 prioritize gaps, right? So what is a gap?

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

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

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

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

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

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

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

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

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

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

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

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

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

20 MS. JOHNSON: That hasn't been
21 completely done. But the closest that I've
22 come so far is in this ideas and concepts grid

1 there are asterisks beside some of the
2 concepts. And the asterisk means that there
3 is at least one measure that hits it to some
4 extent. So, and I don't have a good example.

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

10 MS. JOHNSON: Yes.

11 MEMBER COOLEY: That's good to know.

12 MS. JOHNSON: Yes.

13 MEMBER COOLEY: Thank you.

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

21 But if you think, you know, if it
22 turns out that you pick things that have

1 already been done, again, it may still be a
2 gap if it's been done as a very simple process
3 measure but you want to extend it to an
4 outcome measure or something else. Or maybe
5 even an ACO-level or a population measure or
6 something like that. So there's still room to
7 extend potentially. Ryan.

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

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

19 There are a lot of measures out there
20 that already exist, particularly things like
21 safety measures, falls, some medication
22 reconciliation kinds of things that are out

1 there that really can be applied to the
2 dementia population.

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

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

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

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

20 If a measure also exists, great, tack
21 that on. But focus less on the existing
22 measures or the measurement tool and focus

1 more on the concept right now and getting to
2 the tool later in the next step.

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

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

11 (Laughter)

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

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

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

3 MS. FELDMAN: We're going to break --
4 for the transcript purposes we are going into
5 small groups.

6 (Whereupon, the foregoing matter went
7 off the record at 1:44 p.m. and went back on
8 the record at 3:34 p.m.)

9 CO-CHAIR PERFETTO: Okay, we're ready
10 to get started. Everyone please take their
11 seats.

12 MEMBER COOLEY: Susan Cooley, I'm
13 here.

14 CO-CHAIR PERFETTO: Thanks, Susan.

15 CO-CHAIR FELDMAN: So, we have three
16 groups, three reports. I think it was an
17 engaging and challenging task.

18 And should we go in like
19 chronological order do you think? No, no, no,
20 starting with population at risk. That's the
21 trajectory we're talking about right this
22 moment.

1 Okay, Katie. And since you're not
2 standing by your microphone how is that
3 working?

4 MEMBER MASLOW: Okay, so I'm standing
5 here so that I can look at this. I know that
6 you can't follow. Are you going to move it?

7 CO-CHAIR FELDMAN: A handheld mike is
8 on the way.

9 MEMBER MASLOW: Okay, so our group
10 had two columns. So our first column is
11 population at risk.

12 And we have an idea. This is a
13 concept. It's aspirational. And the idea is
14 some kind of sort of hierarchical system that
15 would start by identifying people with risk
16 factors for cognitive impairment.

17 So this is not looking at the
18 screening row. This is not screening for
19 people with -- looking for cognitive
20 impairment. This is identifying people who
21 are at high risk for developing cognitive
22 impairment and dementia.

1 So that's first. That's this
2 concept. And look, and using a very broad
3 definition of risk factors, of things that
4 could be indicators of risk for dementia.

5 Then, second and connected to that is
6 trying to educate first the public about those
7 risk factors so that people come to understand
8 what creates risk for cognitive impairment and
9 dementia.

10 And then education of the healthcare
11 workforce about those same factors. So what
12 creates risk for cognitive impairment.

13 And along with identifying risk is
14 also identifying or creating a message about
15 the possibility of there's something to do.
16 So, to try to counteract the stigma and sort
17 of fear to say these people are at greater
18 risk but there's also something to do for them
19 if they are identified.

20 Anyone in my group want to say
21 anything else about this one? Okay.

22 So then we talked about in the area

1 of symptom awareness and detection. In this
2 high-risk group, and again, aspirational here,
3 but looking at the high-risk group that those
4 individuals should be screened on a regular
5 basis in a physician office. And screened
6 looking for any indicators of cognitive
7 impairment.

8 So that's one domain or subdomain I
9 guess it is. Is that right? It's a
10 subdomain? Or is it a domain? It's a
11 subdomain. You don't want to say. I see, you
12 won't even look at me about that question.

13 (Laughter)

14 MEMBER MASLOW: Okay, then the second
15 thing is to be -- greater awareness, and this
16 is essentially for healthcare workforce,
17 social service, anyone that would be working
18 with people who might have cognitive
19 impairment, greater awareness that dementia is
20 not just memory problems. So looking more
21 broadly at functional triggers for being aware
22 of possible dementia.

1 And we thought of a lot of things in
2 this area but looking broadly at language
3 issues, at gait kinds of issues, things that
4 aren't what everyone thinks of as memory
5 problems or dementia.

6 Then third -- or let me stop with
7 those and talk about diagnosis. So we don't
8 know whether our area includes diagnosis or
9 that belongs to the next column.

10 But we think that it's very important
11 that detection lead to a diagnostic
12 evaluation, one.

13 Two, that the diagnostic evaluation
14 is intentional and results in a diagnosis.
15 That it occurs in a reasonable amount of time,
16 that being a short time from when there's
17 detection. And that it's documented. So as
18 we go through that I'm sure we're into the
19 next column's area, but at any rate, those
20 diagnostic-related and measure-related issues.

21 And then two more things. That even
22 in the area in the time of symptom awareness

1 and detection family involvement, engagement
2 of family is important. Assuming that it's
3 all right with the person, but that the family
4 at that time is also often anxious, might be
5 depressed are issues for the family related to
6 the detection and diagnosis.

7 And that they need to be -- family
8 members need to be considered at this time.
9 That that's part of quality of care.

10 And then lastly, that as the
11 detection process moves on, and again we see
12 this as sort of a flow from the top on past
13 our area, that there needs to be attention to
14 interventions that can help with quality of
15 life of people who are in early detection and
16 then going into diagnosis.

17 So what have I missed? Nothing else?
18 Mark, anything? Murray?

19 CO-CHAIR FELDMAN: Great job
20 summarizing a very ongoing discussion with
21 many --

22 MEMBER MASLOW: I probably missed

1 some important things, but anyway.

2 CO-CHAIR FELDMAN: Having set that
3 spectacular model of conciseness we're ready
4 to go onto evaluation, initial management and
5 mild cognitive impairment. Right? They were
6 together. So that's our group number 2.
7 Who's going to report that?

8 MS. JOHNSON: I got elected to do
9 that. I'm not sure how that happened, so. I
10 think because it's a little unwieldy with our
11 papers. But my crew will definitely help me
12 out here.

13 I think what we ended up doing and
14 possibly my fault, but I really wanted to keep
15 people separated on our evaluation and initial
16 management, and then go into the treatment.

17 And then after we did that the first
18 time, then we ended up saying hey, a lot of
19 these things are kind of the same except for
20 updating. So, at the end of the day I think
21 we ended up in the same place you guys did but
22 it took us longer to get there. But that's

1 okay.

2 So for a person with dementia. And
3 these aren't necessarily in order of
4 importance. These are just the ones that rose
5 to the top.

6 Needing to know who the proxy
7 decision-maker is. Assessing for personal
8 goals for treatment. Having a care plan
9 documented and not only in the chart but given
10 to the person.

11 The core dementia work-up needs to be
12 done and documented, and along with that is
13 eliminating other causes of dementia.

14 And then finally, connection to
15 supportive services in the community. That
16 was a big one that kind of -- a lot of things
17 went under that one.

18 There may be a couple of others that
19 I'll tell you once I get to the second sheet.
20 Let me give you the caregiver ones. And
21 actually some of these are the same for
22 caregiver but we'll work through it.

1 Having capacity and confidence. We
2 also, the group thought that it was important
3 to assess the caregiver goals for treatment,
4 knowing that the caregiver goals and the
5 person with dementia goals may be different.
6 And knowing, you know, understanding that.

7 The education on what to expect needs
8 to be given to the caregiver. I think that
9 didn't rise to the top for the person with
10 dementia, but that person also needs to know
11 what to expect too.

12 Thinking about caregiver burden and
13 strain. Also, again these aren't really in
14 order, understanding treatment options. So
15 the caregiver needs to understand the options
16 that are there.

17 And then of course the connection to
18 supportive services in the community. That's
19 the same as up above.

20 And then -- so that was what we came
21 up with for the first one, the evaluation and
22 initial management. And then as we walked

1 through the care treatment what we ended up
2 saying again was a lot of these things were
3 the same, but we did figure out a couple of
4 new ones.

5 So, under person with dementia,
6 actually if you just go back to that other
7 slide and just add another bullet under person
8 with dementia. Having a dementia case
9 manager. Is it case manager or care manager?

10 CO-CHAIR FELDMAN: Care manager is
11 generally.

12 MS. JOHNSON: Okay. And then, team,
13 you have to help me with this one.
14 Transition, impacts on dementia, delirium, et
15 cetera. Can you? Right, right.

16 MEMBER CARNAHAN: Yes, I think we're
17 onto the mild and moderate piece now as
18 opposed to initial management.

19 MS. JOHNSON: Yes. So, I think we're
20 just going to group them together. Is that
21 not what we decided? Or do you want to keep
22 them separate?

1 MEMBER REUBEN: Some of them yes and
2 some of them no. So, the ones -- this is one
3 that would actually be in the follow-up stage.

4 MS. JOHNSON: Okay.

5 MEMBER REUBEN: Yes, so that in the
6 follow-up stage anyone who has dementia, if
7 they're transitioning, or they're discharged
8 from a hospital, or to a nursing home, or
9 something like that, the impact of that
10 illness upon their dementia care should be
11 reassessed. That's what we're getting at.

12 MS. JOHNSON: Are you happy with that
13 bullet?

14 MEMBER REUBEN: It's the impact of
15 transition of care. So in other words if
16 they're hospitalized. Or impact of acute
17 illness or change in condition under care.

18 CO-CHAIR FELDMAN: And just a point
19 of clarification. And does the care manager
20 also only refer to the person with mild
21 dementia and not to the -- I mean, to the
22 treatment and not to the -- not to the

1 evaluation and initial management?

2 MEMBER REUBEN: So, this is an
3 artifact of setting these things up
4 arbitrarily.

5 So you would think actually that you
6 would have -- basically the game would begin
7 when there was the initial assessment and it
8 would go on. But the way they were divided is
9 you have this initial assessment and then the
10 follow-up period.

11 So, during the follow-up period you
12 need the dementia care manager at the time of
13 assessment. The dementia care manager does
14 the assessment. There's no role for that
15 person. But it's an arbitrary distinction.

16 CO-CHAIR FELDMAN: All right. But
17 someone's identified early on.

18 MEMBER REUBEN: Right, yes. Someone
19 is identified early on.

20 MS. JOHNSON: Okay, let's see.
21 Assessing medication side effects and
22 effectiveness. I think -- I was thinking it

1 was in both. But I guess it's arbitrary
2 again, right, Dave? It's kind of arbitrary?

3 MEMBER REUBEN: So, it's arbitrary.
4 But here, let's say that they have the initial
5 assessment and they got started on a medicine.
6 And in the follow-up period you'd assess the
7 response to the medicine including adverse
8 effects.

9 MS. JOHNSON: And then for caregiver
10 this is --

11 MEMBER CORDELL: Side effects and
12 efficacy.

13 MS. JOHNSON: And efficacy. Yes,
14 efficacy or effectiveness. Yes, thank you.

15 For caregiver we want to start
16 thinking about health, caregiver health being
17 assessed.

18 And here we recognize that the
19 person, the clinician that's taking care of
20 the person with dementia may not be taking
21 care of the caregiver but yet has some
22 responsibility to do some referrals or

1 something like that so that, even bringing it
2 to their attention that they may need further
3 health follow-up.

4 And then lastly, caregiver
5 participatory decision-making. So the idea
6 there that the caregivers are engaged in the
7 decision-making even at this earlier stage.

8 I think I got them all but does that
9 -- that seems like your list?

10 I think the other thing that we
11 talked about was there's a lot of assessing at
12 that early stage. But knowing that the
13 assessing doesn't happen one time, but it has
14 to be updated. So care plans are updated.
15 Assessments are done again and again.

16 MEMBER REUBEN: I thought the
17 dementia care manager was going to be in that
18 next slide.

19 MS. JOHNSON: Yes, I think it may be.
20 So that where your cursor is now --

21 MEMBER REUBEN: Yes, move that to the
22 next one.

1 MS. JOHNSON: -- can you move that to
2 the second slide?

3 MEMBER REUBEN: Yes. And what I
4 would say for this title, I would change it to
5 Group 2 - Ongoing Care for Mild to Moderate.
6 Makes it a little clearer. So one is the
7 initial assessment and this is the ongoing
8 care.

9 MS. JOHNSON: Yes.

10 MEMBER CORDELL: Right and also like
11 the connection to community resources should
12 get in initial and throughout so we didn't
13 repeat it. So these weren't completely
14 separate.

15 MEMBER REUBEN: So the other thing we
16 had for the ongoing care that didn't make it
17 on this list is the routine reassessment of
18 everything that was on the first. So they'd
19 have to have periodic reassessment.

20 MS. JOHNSON: Yes, right.

21 MEMBER REUBEN: So go to the next
22 slide. Correcting the slides. That's okay.

1 MEMBER CORDELL: So periodic
2 reassessment should be a bullet that's on the
3 second slide. Because the periodic
4 reassessment of everything that's on this
5 slide should happen in the follow-up.

6 CO-CHAIR FELDMAN: Is that it? Other
7 additions to that group? Okay, great.

8 So now we go to group 3 which was
9 care treatment and support for severe dementia
10 and then also end of life and bereavement.
11 Joan, sorry.

12 MEMBER TENO: Great. Okay, we were a
13 group of lumpers. So we're thinking of this
14 as for families in five sort of overarching
15 constructs that would form multi-item
16 composites.

17 So, the first one in this group would
18 be shared decision-making with an advanced
19 care planning composite that would cover a
20 range of activities from informing about
21 prognosis, treatment options and anticipating
22 future decisions.

1 For example, educating people about
2 the use of feeding tubes given that such a
3 high rate of this population is at risk for
4 feeding problems, hospitalizations.

5 The second construct is person-
6 centeredness. And you know, I think this can
7 cover a range of items. But one of the key
8 things that was brought up by the group is
9 that it would include the ability of that
10 person and family to shape choices over their
11 everyday activities. Whether that person was
12 treated with respect and dignity.

13 So this would sort of get at the
14 choices about what would happen for that
15 patient on every day depending on their
16 setting of care and interaction with
17 healthcare providers.

18 Third, if you sort of look at where
19 the money is, the money is in hospitalizations
20 and transitions of care and the lack of
21 coordination of care with those events. And
22 often hospitalizations can be an iatrogenic

1 episode.

2 So, it would be important to look at
3 a trigger for transition in the brief, the
4 family member's perception about how that
5 transition went, how did the care in that
6 hospitalization go.

7 And sort of I saw this as low-lying
8 fruit is to deal with HCAHPS and the fact that
9 HCAHPS now routinely excludes anybody who goes
10 to a nursing home.

11 And I think this would be a case
12 where some valuable information could be
13 obtained about the quality of care for a
14 population that really challenges an acute
15 care environment.

16 Fourth, we realized that caregivers
17 play a very important role. And we see a
18 multi-item composite that would cover
19 everything from the initial assessment done
20 for that caregiver about sort of their needs
21 and expectations to timely communication with
22 the family member.

1 Training for someone who's going
2 home, whether they were provided with the
3 correct amount of information about what to
4 expect and training and support in providing
5 those tasks at home.

6 The responsiveness to their needs. I
7 think one of the cases we heard is how -- a
8 very poignant tale of how our healthcare
9 environment or healthcare system was not
10 responsive in listening to the family member
11 about how to avoid a disruptive episode in a
12 dementia patient.

13 And often we forget the caregivers
14 are probably the best source of information
15 about who that person is and how best to care
16 for that person.

17 And then time and time again family
18 members feel that they're left to advocate for
19 their own in a healthcare system that's not
20 responsive to their needs and expectations.

21 So this notion of a system can create
22 an environment where they don't feel they're

1 always advocating for, you know, I was going
2 to say high-quality care. Often it's just
3 basic care.

4 And then the fifth idea which is one
5 I really like is why not use the family member
6 to comment on how dementia-capable the
7 healthcare system is. They're really sort of
8 an expert witness about what the frustrations
9 are.

10 How did people interact with that
11 patient? Did they make eye contact? Just I
12 think I could see easily a series of
13 composites created which had the family member
14 being expert witness to how that healthcare
15 system interacted and treated that dementia
16 patient hopefully with dignity and respect.
17 Thanks.

18 CO-CHAIR FELDMAN: That's great. Any
19 other additions to that?

20 Okay, so I think now -- now is the
21 challenge of pulling this together. And I'll
22 kind of start it off with one comment and then

1 I'll throw it out to others.

2 I think -- I'll start off the
3 discussion with just one thought that's come
4 up in each of the groups which is that there
5 are clearly some constructs which while they
6 may seem most salient or most poignant for one
7 part of the trajectory they actually are --
8 they rear their heads in one way or another
9 across the person trajectory and the caregiver
10 trajectory.

11 And so it seems to me one question to
12 throw out to the group is do we want to, and
13 the answer might be no, but are there certain
14 really salient things that have emerged from
15 all of these, or that came out in one group
16 which maybe were mentioned in another group
17 but didn't rise to the very top which we might
18 really want to flag as critical concepts to be
19 measured periodically with perhaps different
20 frequencies at different points in time.

21 And then the second thing that also -
22 - I'm not saying anything that's very

1 earthshaking.

2 But the second thing is that there
3 are most likely some things which may be
4 unique or are so salient for one part of the
5 trajectory but not necessarily so salient for
6 others. And that we certainly want to be sure
7 that we don't miss those.

8 And so my question is is that one
9 useful way of thinking about this? What are
10 the kind of commonalities, things, concepts
11 that we think we would like to capture and
12 measure across the spectrum? And others that
13 we believe are uniquely or principally
14 important for one part or another?

15 And so I throw that out. You can say
16 that's ridiculous -- propose an alternative.

17 You lost two sentences there. I said
18 we can throw it out and we can reject it, or
19 we can view those as some organizing
20 principles and way to go. But it was just a
21 way to start discussion.

22 MEMBER SNOWDEN: I mean, I would

1 certainly agree that anything that really can
2 be relevant across the entire spectrum would
3 be better than things that really will have a
4 short life span so to speak within the
5 trajectory.

6 MEMBER REUBEN: I agree. And I think
7 there were some that clearly went across all
8 three. Those include this concept of shared
9 decision-making, participation, patient
10 preferences. Those kinds of things go through
11 all of these.

12 The second one that really goes
13 through all these are the whole idea of
14 caregiver involvement, caregiver support,
15 caregiver -- effects of caregiving on the
16 caregiver per se. I think those got through
17 all of them. There may be some others.

18 MEMBER KAHLE-WROBLESKI: So yes, I
19 think those are some great shared ones across.

20 The one piece we talked about this
21 morning that Joan had brought up, it's the
22 denominator piece.

1 So I think we would need to think
2 separately maybe about the detection piece.
3 And that's okay because I think there are some
4 commonalities across all stages.

5 But I don't want that detection piece
6 to get lost in that because I think that is
7 critical, that's our denominator and that's
8 what is going to drive a lot of this.

9 CO-CHAIR FELDMAN: Other thoughts and
10 comments about the groups' reports back and
11 what's common, and what's distinctive, and
12 what we want to be sure not to lose?

13 MEMBER SNOWDEN: Yes, it seems to me
14 that one of the things that all of the groups
15 did was to actually back up and abstract at a
16 broader level which leaves me wondering what
17 happens to some of the fairly specific and
18 concrete things that are actually on the
19 sheet.

20 And my sense is that they can be
21 incorporated into this but part of me wants to
22 make sure that we don't forget the ones that

1 are actually on here that tend to be fairly
2 specific. Because they'll either need to be
3 consciously put into that or something else
4 done.

5 CO-CHAIR FELDMAN: It would be useful
6 to have an example of that.

7 MEMBER SNOWDEN: So, for example, as
8 a psychiatrist I was really interested in a
9 lot of the ones on behaviors particularly when
10 we get into the course of illness.

11 My group given where we were in the
12 trajectory didn't spend a lot of time on that,
13 but it's clearly I think very important.

14 I see it as one of the signs and
15 symptoms. So to the extent that a lot of
16 these talk about signs and symptoms. I'm okay
17 with saying we don't have to call out every
18 single sign and every single symptom.

19 But I want to make sure that, again,
20 it gets translated into a broader concept,
21 that that's what we're really going to do.

22 CO-CHAIR FELDMAN: One of the

1 concepts that came out of our group, and Mark,
2 you were in that group, is that for people who
3 are not specialists and trained to assess
4 people with dementia and cognitive impairment
5 is that they tend to have a list of a couple
6 of things that they think about that are very
7 segmented, like memory, for example, memory
8 loss, or maybe word recall.

9 And that yet there are a host of non-
10 usual suspects which are usual suspects to a
11 psychiatrist or to a neurologist. You know,
12 falls, gait, all kinds of things that don't
13 get encompassed in everything from signs and
14 symptoms to detection. Presumably in
15 diagnosis they get picked up but then they may
16 be lost farther along the way.

17 So maybe one theme going across is
18 this emphasis on not just focusing on usual
19 symptoms. I don't have an elegant way of
20 putting that. Would that begin to capture
21 what you're --

22 MEMBER SNOWDEN: Yes, that would be

1 perfect.

2 MEMBER HASHMI: I was just going to
3 offer a vocabulary for what Mark was saying
4 and what you were saying is it's a disease
5 with multi-system manifestation.

6 CO-CHAIR FELDMAN: Great.

7 MEMBER HASHMI: And the systems are
8 about not just the body but it's a societal
9 system. And the health macro and micro system
10 as well.

11 CO-CHAIR FELDMAN: Joan.

12 MEMBER TENO: I just wanted to add in
13 addition to thinking about the denominator I'd
14 also think about what is the trigger. So, in
15 terms of specific time periods.

16 So the one thing nice about the
17 HCAHPS example is you probably could construct
18 a denominator, and then you have a trigger,
19 and then you have a set of behaviors that sets
20 up an episode of care. So that I think is
21 really important to think about.

22 As we sort of develop these

1 overarching concepts we need to have them be
2 able to link to a way of identifying the
3 population, but also thinking about what the
4 episode of care and who's accountable for
5 that.

6 CO-CHAIR FELDMAN: Right. And
7 transitions came up in several groups as one
8 obvious trigger. And we actually -- I'm not
9 sure, I think we did use the word "trigger" in
10 our group. The notion of when you identify
11 someone with risk factors what should that
12 trigger and what actions, presumably
13 measurable actions, should that trigger. And
14 then when there's a diagnosis what should that
15 trigger in the way of action.

16 So I think the concept of triggers is
17 implicit in what a lot of people said. And so
18 there could be common measures but then issues
19 around what events trigger the application of
20 particular measures.

21 MEMBER TANGALOS: When I look at our
22 conceptual framework and try to see if we've

1 touched on most of the pieces, not that we
2 have to.

3 I think we did but where I worry the
4 most is we haven't hit much on safety. And
5 when I look at patients I look at autonomy and
6 safety. I look at risk versus dependence.
7 Those pieces kind of balance themselves out as
8 patients go forward.

9 And you know, in our conceptual
10 framework we put safety at the very end. I
11 actually think it fits in before that too.
12 But I don't think we've done a very good job
13 of addressing the issues of safety in any of
14 what we've discussed so far this afternoon.

15 CO-CHAIR PERFETTO: Eric, let me just
16 add to that because I think you're right, I
17 think we didn't cover safety very much at all.

18 But one thing that we talked about
19 this morning that in the conceptual framework
20 it's a little misleading that these are laid
21 out, the domains are laid out horizontally
22 like that. And it was not the intent to say

1 that safety was at the end. It was just the
2 way that they got laid out.

3 MEMBER TANGALOS: No, I understand
4 that. I mean, there's plenty of places where
5 we would have done that.

6 But still, the issue of safety I
7 think is -- it may be because it's a late
8 player to the game. The universe of quality
9 now has to embrace safety.

10 And the next iteration of the
11 National Quality Forum will be the National
12 Quality and Safety Forum. I mean, it's going
13 to be along those lines.

14 But I think we've got to think about
15 it more.

16 CO-CHAIR FELDMAN: Katie, go ahead.

17 MEMBER MASLOW: So, I agree with
18 Eric. I think that in our idea of looking
19 more broadly at what cognitive impairment and
20 dementia mean we started with Mark's
21 discussion about falls.

22 So, very early falls. It's a risk.

1 It's a safety risk. Driving. All of those
2 kinds of things where if we expanded our
3 training and health workforce awareness of
4 those different aspects of dementia we would
5 see more what you're talking about, the safety
6 issues going all the way through I think.

7 CO-CHAIR FELDMAN: Ryan.

8 MEMBER CARNAHAN: Yes, I'll just say
9 we did talk about that. And if it didn't
10 quite make our top five it was right up there,
11 evaluating the safety of the environment. And
12 that kind of went along with the caregiver
13 capacity to take care of somebody when they're
14 not yet in the nursing home.

15 MEMBER TANGALOS: I could wax
16 eloquent on safety a little bit longer. When
17 we start to teach about quality and safety the
18 quality universe is oftentimes very difficult.
19 It's in the eye of the beholder. And here we
20 have the beholders and we're all looking at
21 this stuff.

22 The safety environment, the safety

1 universe is actually easier to measure
2 outcomes. I mean, it's X's and O's. It's yes
3 or no. It's errors in a given substrate.

4 So again, I think even for the
5 purposes of this exercise and as the next
6 couple of years go forward continuing to think
7 about safety as a measurable outcome is really
8 the way to go.

9 CO-CHAIR PERFETTO: I just want to
10 add my personal note on the safety issue.
11 Because I think for me over the 15 years that
12 I was caring for my husband I started with the
13 goal of keeping him functional.

14 And then over time that goal changed.
15 And it was no longer the goal was to keep him
16 functional, it was to keep him safe and have
17 a good quality of life, and to be sure that
18 people around him were safe. Because if his
19 behavior became bad it wasn't only his safety,
20 it was others' safety too.

21 So I think over that period of time
22 your goals change. And I think as you go down

1 the trajectory safety goes up when other
2 things start to go down.

3 CO-CHAIR FELDMAN: Ryan, are you
4 going to talk to the safety? Your card's up.
5 No.

6 So, I was just going to comment that
7 outside of institutional settings this issue
8 of accountability around safety and the
9 tradeoffs between autonomy and safety become
10 particularly sensitive issues for providers.

11 Because for most of the time the
12 person under their care is actually not
13 physically under their care. And so I think
14 it's a huge area for sophisticated and
15 developmental thinking about that. Because I
16 think that's really been very difficult in the
17 non-institutional.

18 MEMBER TANGALOS: Actually, when you
19 look at -- I mean, we've looked at assisted
20 living providers who over the last 40 or 50
21 years have gone broke with a building.

22 And they usually go broke with a

1 building when it gets down to somebody moving
2 in and saying what do I want out of this
3 building. Do I want the Jacuzzi? Do I want
4 the chandeliers? Or do I want grab rails in
5 the bathroom? And people make those
6 decisions.

7 And healthcare is honestly way behind
8 in the safety universe. When you watch car
9 commercials today the implicit and explicit
10 message is you are not going to die when you
11 crash this car. That's the story.

12 CO-CHAIR FELDMAN: Joan.

13 MEMBER TENO: I think safety is a
14 little bit difficult. It depends on sort of
15 the population that you're dealing with.

16 I think the home population is a very
17 difficult population in that we tend to allow
18 people to have a lot of autonomy and allow
19 them to sometimes live in a less than perfect
20 environment because that's based on their
21 views, choices and values.

22 The other thing I would worry about

1 is when you think about safety as sort of a
2 checkbox measure for some populations,
3 especially those people who are dying, some of
4 the checkbox measures that were developed for
5 the acute care hospital are not really
6 transferrable to that population.

7 You know, sometimes we really don't
8 move people while they're actively dying even
9 if that may increase their risk of pressure
10 ulcer, UTIs, things like that.

11 So I actually think safety, some of
12 the safety measures we have need to be really
13 thought through on how they're applicable to
14 this population and where people are in their
15 disease trajectory.

16 CO-CHAIR FELDMAN: And our group
17 certainly didn't have a solution to this but
18 we talked a bit about the issue of
19 stratification and how that relates to who's
20 in the numerator and the denominator for
21 particular measures.

22 And I think that from a feasibility

1 or acceptability point of view the issue of
2 stratification is going to be very important.

3 And I think that done right it could
4 really be an incentive for providers to do a
5 better job of actually detecting people,
6 particularly in the early ages, and reporting
7 people with dementia. David?

8 MEMBER REUBEN: Yes, let me just
9 respond as well about the safety issue.

10 Maybe it was just our group that we
11 had a larger charge or that we just generated
12 a lot of ideas.

13 But I think one of the issues is
14 there were a lot of clearly ideas, that we
15 endorsed that we really liked, but we only had
16 10 bullets and we had only 10 dots. And some
17 of them fell below that threshold of the five.

18 So it doesn't mean they're not good
19 ideas. And if we had -- I think all of them
20 we would have elected to have kept. So once
21 again, this is something, an artifact of the
22 process.

1 But we all felt it was a good idea.
2 Not enough of us voted for it to get it to the
3 final five.

4 CO-CHAIR FELDMAN: Mark.

5 MEMBER SNOWDEN: Yes. As I looked at
6 the things that are listed under safety if I
7 had to pick things out that to me would have
8 risen to the top I think certainly falls would
9 have been up there. I think environmental
10 safety would have been up there. Certainly
11 medication issues safety would have been up
12 there. Wandering and getting lost. Safe
13 return.

14 The things that I didn't see on here
15 that again as a psychiatrist come to play are
16 unsafe decisions because one isn't attuned to
17 decisional capacity.

18 I see a lot of people who make
19 decisions and I get called in to evaluate
20 their capacity to make that decision when it
21 should have happened way, way before it
22 actually did.

1 The other would actually be suicide.
2 That sort of goes hand in hand with depression
3 as a safety factor.

4 CO-CHAIR FELDMAN: We're going to --
5 when Eleanor takes over we're going to be
6 prioritizing across these measures, right.
7 So, if you've got thoughts on this -- so if
8 you've got thoughts and issues that really
9 came out of your group that you want to be
10 sure are really up there this is the time.

11 Chris, if there was anything
12 particular on the detection side I think you
13 mentioned.

14 MEMBER KAHLE-WROBLESKI: I would
15 encourage the group to look at the pieces that
16 we had created for detection and maybe pull a
17 few of those out.

18 Again, I feel like it's great to have
19 a conversation about quality indicators for
20 dementia patients across all stages. But if
21 they're never identified as a dementia patient
22 it's not going to activate any of these

1 supportive services and care services and
2 coordination of care.

3 So inasmuch as we can label people
4 appropriately so that they can become part of
5 the system and have all of those services
6 activated, to me that's the critical piece.
7 I don't know if our group got all the right
8 ones, or if the right concepts were there.

9 But I would encourage people to go
10 and have a look and see which of those around
11 the detection piece are maybe the most
12 feasible or manageable right now that we could
13 get started on and recommend moving forward
14 toward.

15 And the other piece of it too, and I
16 know the U.S. Preventive Task Force put out
17 their recommendation that we shouldn't be
18 doing any screening.

19 I would just say that we weren't
20 talking about screening. We were talking
21 about detection.

22 And the other piece of it for our

1 group too I think was around the evidence
2 base. And there may not be an evidence base
3 for all of the recommendations that we would
4 make.

5 Although -- I won't speak for the
6 group. I'm comfortable with that if it means
7 that we have to develop that. But that's
8 something we need to know as well.

9 So keep that in mind too. We may not
10 have the evidence base now but if there are
11 things that we need to do to create that then
12 let's be aware of that as well.

13 CO-CHAIR FELDMAN: And I think
14 implicit in the discussion of that group was
15 that the evidence base, you know, we're not
16 talking at this point about reducing --
17 certainly not reducing mortality. You know,
18 we're really talking about effectiveness in
19 terms of quality of life, advanced planning
20 and that kind of thing. Katie.

21 MEMBER MASLOW: I just want to
22 reinforce what Chris said. I think that

1 because of the way that we talked about the
2 hierarchical structure we didn't say as
3 strongly as some of us would want to say the
4 importance of detection.

5 So, none of this is going to happen
6 without detection. And if you're in a system
7 where patients or people come to you then you
8 can give them good care without detection
9 happening. But by and large you can't. So to
10 me detection is the first and most important
11 thing that needs to happen.

12 And the way that we were thinking
13 about it was that if you are starting with
14 people who you're envisioning are at risk for
15 various reasons you have a better chance of
16 detection.

17 CO-CHAIR FELDMAN: Murray.

18 MEMBER GROSSMAN: Our group also
19 spent sometime discussing the issue of
20 education and the way that that can occur at
21 several levels, and the advantages of
22 education.

1 And it's not just education in terms
2 of having somebody delivering a competent
3 message, but it's also being able to deliver
4 that message in an effective way.

5 And it depends on the kind of thing
6 that you want to communicate and the things
7 that you want to communicate. You have to
8 figure out what the costs are relative to the
9 relative benefits.

10 And so some things we thought were
11 effective to try to communicate broadly
12 including making significant efforts to
13 penetrate elements of the community where they
14 don't have a lot of exposure to TV or to other
15 kinds of media, to the internet, other things.

16 And I'm thinking here of issues
17 related to very, very common healthcare risks
18 or other kinds of demographic risks that can
19 be the kind of things you have to worry about
20 in terms of trying to prevent dementia from
21 occurring. So, education becomes a very
22 important kind of thing to talk about.

1 And education also plays an important
2 role not simply in terms of helping to
3 facilitate detection, but it's also important
4 in terms of being able to convince
5 individuals, family members, caregivers, folks
6 in the community that there is some benefit to
7 thinking about these kinds of risks. That
8 it's not the no, let's take the approach that
9 you can't do anything about it, but instead
10 that we can do something. So it is worthwhile
11 trying to do these detection efforts.

12 MEMBER COOLEY: This is Susan Cooley.
13 Sorry just to butt in. I don't have a tent
14 card to hold up.

15 I just wanted to mention also I seem
16 lately to be hearing a lot more about risk
17 factors and measurement of risk factors and
18 then screening for risk factors and kind of
19 moving further and further away from just
20 recognizing overt signs and symptoms.

21 So I always want to put a plug in for
22 the education of individuals, education of the

1 public for individuals and families and
2 providers on what are the signs and symptoms.

3 And then having them recognized,
4 detected, the signs and symptoms detected.
5 And then that prompts an evaluation.

6 So I agree that detection and
7 evaluation is the beginning part before you
8 can get into the rest of the measures related
9 to good care.

10 But I personally would like to see
11 more focus on the recognition of actual overt
12 signs and symptoms because that seems to be
13 missed quite a bit.

14 And not to take anything away from
15 the developing area of risk factor
16 identification and understanding, but risk
17 factors is a very complicated area.

18 And I would not like to see a lot of
19 effort put into that at the expense of
20 measures that would help prompt people to
21 actually recognize overt signs and symptoms.
22 Put that plug in.

1 CO-CHAIR FELDMAN: Okay, Joan has her
2 name raised. And I think Eleanor wanted to
3 say something. And then I think the fateful
4 time to vote will be upon us.

5 MEMBER TENO: One of the things to
6 think about, everybody will agree that
7 detection is important. But how do we measure
8 it? You know, if they're not detecting it how
9 do we get that denominator for that?

10 And then the other question is who's
11 accountable? And that sort of puzzles me on
12 how to go forward with a measure with those
13 concerns.

14 CO-CHAIR FELDMAN: David, you're
15 going to have the next to last word. And then
16 Eleanor will have the last word.

17 MEMBER REUBEN: Actually, you'll be
18 appreciative because it actually goes back to
19 something you said earlier.

20 That whole idea is before we do this
21 voting are there things that we can collapse
22 so we have less voting to do. We have less to

1 vote off the island.

2 And so, and I think there is. I
3 think there's a fair number of things that we
4 can -- so we have less to get rid of.

5 The second actually relates a little
6 bit to what Joan was saying. There are two
7 areas. One is importance. Actually, there's
8 probably three areas.

9 One is importance. A second is how
10 much evidence there is behind it which NQF
11 will probably use the trump card anyhow.

12 And the third is practicality. You
13 know, is it really feasible to do this. In
14 other words, are you going to have a
15 meaningful measure out of it in the long run.

16 And I think those things, they don't
17 always jive. And so when we do this kind of
18 dot exercise we really need to think about
19 what the dot is -- which of those things is
20 the dot measuring. So, that's it.

21 CO-CHAIR PERFETTO: Well, and David,
22 my last comment is going to tie into what you

1 just said in a couple of ways I think, maybe.

2 One of the things that I learned in
3 the group exercise also was that we also need
4 to be really clear about our definitions and
5 what we're talking about.

6 And that there are terms that we
7 throw around and we think everyone knows what
8 we mean and then you realize, wait a minute,
9 you and I were talking about completely
10 different things.

11 So I think Lynn said long-term care
12 and in my mind long-term care means nursing
13 facility. Long-term care facility. And she
14 was using the term in a completely different
15 way.

16 And so I think one of the things that
17 we really have to be careful of too in this
18 conversation is not only how we're balancing
19 out the criteria because some are going to pop
20 up higher in other areas. And so that's a
21 little bit hard to vote on.

22 But it's also whether or not we're

1 all clear that we're all talking about the
2 same thing.

3 So with that said it's time for
4 voting. We're going to give everyone four
5 votes.

6 So, we're going to give you different
7 colors and we're going to start at the top
8 with the orange color. And it has the highest
9 weight and the yellow has the lowest weight.

10 So you're going to vote for the four
11 things across all of these that you think are
12 your highest priority giving highest weight to
13 orange, lowest weight to yellow. Now, that's
14 the first assignment.

15 The other is that we know that you're
16 going to complain and say some of this doesn't
17 work because there are things on here that are
18 so important within a category they can't be
19 neglected.

20 So if you feel that way about
21 something within a category you can take a
22 blue and use a blue within a category to then

1 -- you don't have to, it's if you want to --
 2 use a blue to give a vote to something that
 3 you think stands out in a category that it
 4 should not be missed. Okay?

5 CO-CHAIR FELDMAN: One blue?

6 CO-CHAIR PERFETTO: Well, I think
 7 people can take more than one blue if they
 8 like, but the blue is kind of -- you have to
 9 feel strongly about the blue. Okay?

10 MEMBER TENO: Other than blue are
 11 supposed to be for individual recommendations?

12 CO-CHAIR PERFETTO: You have four
 13 votes for anything from group 1, 2 and 3.
 14 We're going to get the highest four out of all
 15 of those.

16 MEMBER TENO: So what is the blue
 17 then?

18 CO-CHAIR PERFETTO: The blue is you
 19 feel strongly that something within a
 20 category, not across all of them, but
 21 something that's in detection is so important
 22 for detection that it needs recognition and

1 that might get lost because we're voting
2 across all of the categories.

3 MEMBER TENO: So we basically have
4 five votes.

5 CO-CHAIR PERFETTO: You have five
6 votes.

7 CO-CHAIR FELDMAN: Karen, I do think
8 it would be useful for people who don't fully
9 trust the democratic process for you and, you
10 know, those of us who are the republicans with
11 the small R, not the capital R, you know, and
12 then those of us who are the democrats with
13 the little D. Can you explain sort of
14 what -- I know we're going to review all this
15 tomorrow and so forth. But what happens after
16 this? And particularly in light of the issue
17 of things that may -- one may vote for them in
18 one place so one wouldn't vote for them in a
19 -- you know, the overlapping issues.

20 MS. JOHNSON: I think it's a little
21 tricky because -- and tell me, Juliet, did you
22 guys put on the sticky notes exactly as we had

1 them?

2 CO-CHAIR PERFETTO: Everything that's
3 been on the slides. Yes.

4 MS. JOHNSON: Okay. The tricky part
5 is I think there was some overlap, right,
6 across. So, I think the only thing that makes
7 me nervous is that somebody will vote for it
8 over here, but the same thing is over here.
9 And it won't get voted on.

10 MEMBER BAYLIS: Can I make a
11 suggestion?

12 MS. JOHNSON: Sure, I'm open.

13 MEMBER BAYLIS: Could we go through
14 each item? Because I see numbers over there
15 and then I see little lines. So I'm not sure
16 which items are up for vote and how they're
17 grouped.

18 So if we could, number one, address
19 your first issue, go through each item and
20 eliminate any duplicates, or anything that's
21 related put them together into one item.
22 That's the first thing.

1 And then the second thing is to take
2 a different color marker and go A, B, C, D on
3 each item, each grouping thing that we would
4 be voting on.

5 MS. PRINS: So I think rationally it
6 makes sense. I think from a time-wise I'm not
7 sure how you want to do that.

8 CO-CHAIR PERFETTO: Well, I do think
9 we can number things so that we know what is
10 up for -- which lines are separate and
11 distinct from one another. So we can number
12 them.

13 But I think the other thing is after
14 we've voted we can -- if it says, you know,
15 shared decision-making on this one and we've
16 got shared decision-making someplace else
17 we'll pick it up and put it in there.

18 CO-CHAIR FELDMAN: And similarly, if
19 it doesn't say shared decision-making on one
20 of the others, and yet there was clearly
21 discussion in the group, the fact that it got
22 a lot of votes on there it seems to me would

1 suggest that it would then be visited in light
2 of at what points on the trajectory might
3 shared decision-making be assessed.

4 So even though it doesn't necessarily
5 appear in another one if it's a high priority
6 item one would hope that we would then
7 consider more than one point at which we would
8 do that. Does that make sense?

9 MEMBER CARNAHAN: And these are
10 healthcare system or healthcare provider
11 quality metrics, right? So if we're seeing
12 something that looks like it's more of a
13 public health thing, for example, the
14 awareness of the population, we should not
15 maybe.

16 CO-CHAIR PERFETTO: Yes. I think our
17 goal today was something that had to do with
18 the patient with dementia and the caregiver.
19 So, if something seems like it's maybe a
20 little bit too broad then we probably would
21 not -- don't vote for it.

22 CO-CHAIR FELDMAN: And I think that

1 almost inevitably will turn up tomorrow as one
2 of the parking lot issues, how do we address
3 those things. At least in the report.

4 MEMBER BAYLIS: If we talk about
5 number one then we'll know what number one is.

6 CO-CHAIR FELDMAN: Oh, you didn't
7 abandon your mike.

8 MEMBER GROSSMAN: So, I'm a little
9 confused maybe about the process.

10 So, are we all kind of like voting
11 now and then we're going to discuss tomorrow
12 the ranking and then vote again? Which would
13 be a nice thing to do.

14 CO-CHAIR PERFETTO: I think we're
15 voting now and we're going to discuss again
16 now. And if we have too much of a spread
17 hopefully the discussion will help us get to
18 a little bit of narrowing. Or maybe not. And
19 so if we need to vote again today we can.
20 We're just going to see how the voting and
21 what the spread looks like once the voting
22 takes place. That's been the plan. Correct,

1 Karen?

2 MS. JOHNSON: Correct.

3 CO-CHAIR FELDMAN: And I don't think
4 anyone would object to staying 15 minutes
5 longer or whatever. We're a captive audience
6 today.

7 MEMBER TENO: So can I ask about the
8 motivation of getting down to five or
9 whatever? This much smaller number. I mean,
10 why? What if there were 20 or 25 measures
11 here? What would be wrong with that?

12 CO-CHAIR PERFETTO: If there are 25
13 that's okay. It was just a matter of trying
14 to get some priorities and to try to -- where
15 there are opportunities to lump them, we'll
16 lump.

17 But if there are -- we're not going
18 to throw any of it away. None of it gets
19 thrown away.

20 CO-CHAIR FELDMAN: And also think
21 about it. There are so many people in the
22 room that if we each vote on five things there

1 are going to be concentrations of things and
2 it's going to be on five measures. So I think
3 this was just a vehicle for the discussion
4 groups to, if I understood.

5 MEMBER BAYLIS: So you want to be
6 able to see consensus, the degree of
7 agreement? Like we all, you know, there was
8 a large number of us had our dots on number
9 nine. So that's like, you know, really
10 consensus there.

11 CO-CHAIR PERFETTO: There's something
12 going on there.

13 MEMBER TANGALOS: I have to kind of
14 side with David on this. This is a nice
15 framework that we've put together. And I'm
16 not ready for Sophie's Choice. It just -- no,
17 it actually doesn't seem that the winnowing
18 process is necessary right now.

19 MEMBER JANICKI: What you might be
20 suggesting is do a staff effort overnight to
21 winnow it down to some broad categories and
22 commonalities.

1 And going back to your concept of is
2 it lumping or clustering?

3 MEMBER TENO: Lumping.

4 MEMBER JANICKI: Lumping. And then
5 tomorrow we take a look at those lumps and see
6 how much we want to weight them.

7 It just seems like it's so broad that
8 even if you have this group you're not going
9 to get too many items with the same hit.

10
11 CO-CHAIR PERFETTO: I think that's
12 going to be the staff's call on how they want
13 to manage that.

14 MS. JOHNSON: Yes. I'm just looking
15 at group 1. Yes, that's a lot.

16 I mean, I think at the end of the day
17 one of the things that we do want to be able
18 to give HHS -- and I agree, we've done a lot
19 of great work. So, by definition everything
20 that we've discussed today is a priority to
21 some extent.

22 But if HHS wants to write contracts

1 in the next couple of years for measure
2 development and give some direction for
3 measure development what kinds of directions
4 should they give?

5 So, maybe 25 is where we land, but
6 that might not be exactly where HHS needs to
7 be. You know, they probably don't have the
8 money for 25 contracts.

9 (Laughter)

10 MS. JOHNSON: So, you know, I know
11 it's painful to try to winnow down but I think
12 it might be worth the exercise.

13 And if we can't get there then we
14 can't get there. And that's useful
15 information as well.

16 MEMBER COOLEY: This is Susan Cooley.
17 I just sent to Karen my four votes just
18 assuming that we do have to have four.

19 I agree it's difficult and you may
20 end up having a much longer list with the
21 number of votes of each. And you have some
22 cutoff at some point. And it may be beyond

1 four.

2 But at any rate I just sent a four
3 and then some blues, standout items in
4 addition to the four.

5 CO-CHAIR PERFETTO: Thank you, Susan.
6 Ryan, you were next.

7 MEMBER CARNAHAN: I was just going to
8 note that some of these may have quality
9 metrics too. And so we may end up, you know,
10 if person-centeredness is something that's
11 really been addressed we may end up picking
12 that because we think it's important but
13 something else already exists.

14 And then I don't know exactly how
15 this is going to all fall out in the end but
16 we might want to consider that tomorrow.

17 CO-CHAIR PERFETTO: Joan.

18 MEMBER TENO: I actually think there
19 are some things that are up on the list which
20 probably need to come off the list.

21 So, for example, educate healthcare
22 workforce. That's a wonderful goal, it's

1 something we all should do, but I don't know
2 if I would make that a quality metric.

3 CO-CHAIR PERFETTO: I guess I would
4 say that -- want to just turn it around and
5 say what if we rephrased it and it said the
6 dementia knowledge of the healthcare
7 workforce. Is that?

8 MEMBER TANGALOS: I've got that same
9 problem too. Because I've got to go back to
10 the Alzheimer's plan. And a lot of these
11 things that we've got, there's capacity-
12 building in them. There's a lot of capacity-
13 building.

14 But I'm not convinced that that's our
15 task here. I mean, I'm really not sure it is.

16 MEMBER KAHLE-WROBLESKI: Eleanor, can
17 I? And we had a brief conversation about this
18 in our group. And I think the importance of
19 having that up was more for parking lot than
20 this group necessarily solving it, right?

21 So, I would agree that the broad
22 educational kinds of efforts probably don't

1 lend themselves to quality but in the end are
2 going to impact that. And so we can put them
3 in a parking lot and not have that be part of
4 the vote.

5 CO-CHAIR PERFETTO: Do we want to go
6 through an exercise of putting -- going
7 through these and saying what belongs in the
8 parking lot? Before voting takes place.

9 MEMBER BAYLIS: Then don't vote for
10 it.

11 CO-CHAIR PERFETTO: I agree, but it
12 might make voting easier if we're voting on
13 less than 30.

14 MEMBER BAYLIS: I have another
15 suggestion if I could. I usually use a rule
16 of thumb. You get one-third. Your number of
17 votes is one-third of the list. So that would
18 be 10 votes. No? That's generally, that's
19 pretty typical.

20 CO-CHAIR PERFETTO: But I was -- does
21 anyone feel strongly about eliminating things
22 off this list before we start? Or not? I'm

1 not hearing or seeing --

2 MEMBER REUBEN: I mean, I'm okay with
3 it because I haven't heard that anything that
4 doesn't get voted is eliminated. It's just
5 that we now see where our initial ranking
6 went. And so I'm comfortable.

7 CO-CHAIR PERFETTO: Hearing that the
8 intent of some of these groups was not -- that
9 these would be parking lot items. So, why
10 would we vote on them if that was the group's
11 intent? Should we do that, or does it matter
12 at this point?

13 I don't see any enthusiasm. It's
14 late in the day and everybody just wants to
15 get out of here.

16 All right, then. Here's your
17 opportunity to get out of here. Take your
18 stickers and vote.

19 (Voting)

20 MS. JOHNSON: And we have a little
21 bit of break built in so feel free to do a
22 break, bio break or have a snack. There's

1 still cake left.

2 MEMBER COOLEY: Do you know when
3 you're going to resume?

4 MS. JOHNSON: What do you think,
5 Eleanor?

6 MEMBER COOLEY: I assume that they're
7 voting?

8 CO-CHAIR PERFETTO: Yes, everyone's
9 voting right now and there's a little time
10 built into the schedule for everyone to have
11 a little break if they need it right now.

12 We do have someone who will be
13 joining us on the telephone for public comment
14 at 5:15 and we're trying to get in touch with
15 him to see if he might be able to join a
16 little bit earlier.

17 But if we take a little bit of a
18 break now and come back, have a little
19 discussion about where our dots are falling
20 that should tie into the 5:15 public comment.

21 MEMBER COOLEY: And Karen got my
22 dots? This is Susan. Karen got my votes?

1 MS. JOHNSON: Thanks for reminding me
2 though. I need to put those dots up.

3 CO-CHAIR PERFETTO: Susan, your dots
4 have been put up.

5 MEMBER COOLEY: Oh, thank you.
6 Appreciate it. I may have to leave shortly
7 before 5:30 but I'll hang in as long as I can.

8 CO-CHAIR PERFETTO: There are blue
9 dots here if anybody wants to use the blues.
10 If you feel very strongly that something is
11 very important to a particular group, that it
12 stay there, then use a blue dot.

13 MS. JOHNSON: You can consider this
14 break. We're just talking amongst ourselves.

15 MEMBER COOLEY: Thank you.

16 (Whereupon, the foregoing matter went
17 off the record at 4:50 p.m. and went back on
18 the record at 4:57 p.m.)

19 CO-CHAIR PERFETTO: Okay. So we were
20 just discussing that we do see clustering
21 where people did pick -- a lot of people
22 picked some favorites. And there are a number

1 of places where there can be some
2 consolidation.

3 So the staff is going to take a look
4 at this tonight and they're going to present
5 the results to us tomorrow with some lumping
6 together of some of the things that we see up
7 here grouped and then with the counts on what
8 got the heavier voting.

9 But I think it looks pretty much like
10 we've got a lot of grouping so we're not in
11 too bad of shape. I think we can manage this.

12 We -- did you have anything else you
13 wanted to cover while we wait for George?

14 MS. JOHNSON: We didn't, other than a
15 couple of these things over here it would be
16 nice to hear from you in terms of any
17 additional parking lot issues that we want to
18 cover tomorrow.

19 We have a list that we're pretty sure
20 we want to talk through but maybe now is the
21 time to make sure that we hear from you about
22 your parking lot issues. If you have any.

1 MEMBER TANGALOS: We've talked a
2 little bit about population management. I
3 think it's a little closer to our task than
4 capacity-building.

5 But again, it's a new concept that's
6 out there. It's hit at in a bunch of
7 different places.

8 But again, if we're going stay, or
9 try to stay ahead of the curve, I mean
10 population management is what ACOs are talking
11 about, what we in general are talking about.

12 And it's that link that we struggle
13 with between the clinical systems and the
14 community systems. So, anything that we can
15 do to further identify how to manage a
16 population probably does a better job of
17 linking what is now de-linked from the
18 healthcare system and the community resource
19 base.

20 CO-CHAIR PERFETTO: Bill?

21 MEMBER STAPLES: Yes, I just wanted
22 to make sure that Eric's talk about safety was

1 included in the parking lot issue. I think
2 that's big. And I would have liked to have
3 had it to put a dot on today.

4 MEMBER HASHMI: Point of
5 clarification, Eric. When you say population
6 management you're not talking about population
7 health?

8 MEMBER TANGALOS: It can be part of
9 it. But again, I think as we think about what
10 to do with a population as health plans start
11 to think about what to do with populations.

12 I know our planning actually really
13 does involve community engagement, much more
14 than ever before. And if that word "community
15 engagement" is the word you want to make the
16 link, that's fine.

17 But that is the interface. That is
18 where the medical piece becomes part of the
19 community piece and where things get done.

20 MEMBER HASHMI: So what you're
21 talking about is social determinants that
22 contribute to the overall health status.

1 MEMBER TANGALOS: Part of it. That's
2 just part of it.

3 But I mean, you could go back to the
4 safety issue. I mean, we know this from the
5 previous White House Conference on Aging. We
6 have the most terrible public transportation
7 system in the world. So, for a healthy
8 population it needs sidewalks and public
9 transit.

10 CO-CHAIR PERFETTO: Other parking lot
11 issues?

12 MEMBER TENO: Yes. I just, I want to
13 re-raise that issue about the valence and the
14 evidence and the practicality. I think those
15 are issues that are too easy to dismiss. I
16 think they're too easy to dismiss. And I
17 think I want to make sure that they stay on
18 the table.

19 MEMBER GROSSMAN: So, this is where
20 our educational issues belong, the ones from
21 the group 1. Where you're talking about
22 education in terms of the population being

1 able to recognize at large what kinds of
2 things represent risk factors. Educating
3 health workers. And so worry about falls as
4 possibly an early marker for dementia, that
5 kind of thing.

6 CO-CHAIR PERFETTO: Do we have a list
7 of some of the other things that we've been
8 collecting from earlier today? That we could
9 just read off to be sure that we've covered
10 everything. Chris?

11 MEMBER KAHLE-WROBLESKI: For the
12 parking lot I think too we had brought this
13 up. Part of it was education, but -- and I'm
14 not sure if any of these on the list would
15 fall under that.

16 But if there were some -- if there
17 are any quality indicators that maybe aren't
18 at a physician or healthcare system level,
19 that are more in social care system level, to
20 make sure that we're pulling those out.

21 And if it's not the purview of this
22 group that we make sure that it's channeled to

1 the right group to address those.

2 CO-CHAIR PERFETTO: That is something
3 that we would use to help instruct the staff
4 tonight and kind of lump those together in a
5 separate place so that we can have some
6 discussion about those separately tomorrow, if
7 something is more on that population community
8 level versus our charge of patient and
9 caregiver.

10 CO-CHAIR FELDMAN: I was just taking
11 notes during the discussion. We had
12 discussion of the numerator-denominator
13 issues.

14 We had discussion of personalized
15 measures and creating some kind of a composite
16 of goals on the one hand and outcomes on the
17 other.

18 I think -- well, we talked about a
19 family-centered health assessment but I think
20 that's on the list.

21 Coordination between the healthcare
22 system and the long-term services and support

1 system. Which goes way, way beyond the 5
2 percent in nursing homes.

3 Let's see what else. Those were the
4 -- and the education one.

5 MS. MYERS: Other things that I've
6 noted just throughout the day is the issue
7 around the proxy and who's reporting. The
8 individualized measure approach. That was
9 already mentioned. And accommodations for
10 people with dementia, the structural measures.

11 CO-CHAIR PERFETTO: Ryan.

12 MEMBER CARNAHAN: I don't know if it
13 fits here but the consideration of existing
14 measures that are particularly important for
15 people with dementia.

16 CO-CHAIR PERFETTO: And keep in mind,
17 our charge is not to come up with a new list.
18 It's to include all of those kinds of things,
19 but start fresh with a blank piece of paper
20 and not confine ourselves to existing or non-
21 existing. Katie?

22 MEMBER MASLOW: I think that the

1 education one, Murray's education, actually
2 should be connected to the first one. So that
3 we're talking about clinical and community
4 systems link, and that the end is basically
5 going the other way.

6 So if you start in the community as
7 we discussed it, creating greater awareness
8 and knowledge about cognitive impairment and
9 risk factors and so on. And then you go to
10 clinical. So it's the other end. Maybe I'm
11 being incoherent.

12 But anyway, I think that it's
13 connected there, that there's a community
14 side, sort of a public health community side,
15 there's clinical and then there's community
16 agencies.

17 MEMBER CARNAHAN: I don't know that
18 the providers can be ignored in the education
19 piece though. I mean, just knowing how we've
20 tried to promote better delirium care at our
21 hospital and people still just don't get it in
22 a lot of cases. Even though they're getting

1 screened, they're getting identified, the
2 providers don't know what to do.

3 CO-CHAIR FELDMAN: Mark mentioned the
4 stroke awareness campaign which I think is a
5 community effort but it's also pervaded the
6 provider community as well. And so we had
7 some discussion of that.

8 CO-CHAIR PERFETTO: We only have to
9 stall for about six more minutes.

10 Well, do you want to talk about that?
11 It was someone that we had invited to come and
12 speak today who wasn't able to come. And so
13 we offered him the opportunity to give a few
14 comments during the public comment period.

15 So I don't think that it's because
16 he's commenting because he has anything
17 controversial to say. It was because he
18 wasn't able to make it.

19 MEMBER HASHMI: That's what I was
20 trying to figure out, if he was an important
21 stakeholder from a perspective. Thank you.

22 MS. MYERS: I can comment about

1 dinner tonight.

2 CO-CHAIR PERFETTO: Oh, that's a
3 great idea.

4 MS. MYERS: So, there's dinner
5 reservations at 6 o'clock at a restaurant
6 around the street called Mio. It's 1100
7 Vermont Avenue. We can provide you exact
8 directions. But it's one block over. And we
9 hear it's very good so you all are invited to
10 that tonight. At 6 o'clock, so 40 minutes.

11 MS. JOHNSON: And the purpose of that
12 is just to give you a little bit of more
13 informal interaction with each other if you
14 care to do that. Some committees really like
15 it so we wanted to offer that to you.

16 Juliet, right now it's under your
17 name, is that right?

18 MS. FELDMAN: It's under my name.

19 MS. JOHNSON: It's under Taylor's
20 name. It's Taylor Myers.

21 MEMBER REUBEN: Just while we have a
22 couple of minutes I've been thinking all day.

1 Some of what Eric said this morning about
2 NAPA. HCAHPS has been mentioned several
3 times. And I think CG-CAHPS I would throw
4 into the same boat.

5 And somehow figuring out to the
6 extent that those exist there's some overlap
7 with what we're trying to do. And so I think
8 thinking about how those things that are
9 already out there can potentially be used to
10 further this would also be pretty helpful.

11 CO-CHAIR PERFETTO: Harmonization.
12 Okay, thank you.

13 MEMBER TENO: You might want to see
14 how often dementia patients are excluded in
15 the original CAHPS survey and health plans.
16 It might be interesting to tell you how much
17 of a population you already have.

18 CO-CHAIR PERFETTO: D.E.B., is that
19 something that you'd be able to help with?

20 MS. POTTER: Yes. It's also possible
21 to sort of look at what percent of the
22 hospital population among age groups get

1 discharged to nursing home and then overlay
2 that on the CAHPS and saying well, among the
3 population 80 and above we're mixing X
4 percent. You know, you can look at it that
5 way also.

6 MS. JOHNSON: So, a couple of other
7 things that we had on our parking lot issue
8 for tomorrow, just to plant this in your mind.
9 We've already talked about it quite a bit, but
10 it's anything about assessing quality through
11 the lens of dementia.

12 So, again, I'm not sure if we quite
13 got it on these dots or not, but what might
14 that look like, what kind of recommendations
15 might come out of that.

16 And another one that was on the list.
17 I think we're talking a lot about evidence now
18 and feasibility now and that sort of thing.
19 But what about five years from now if the
20 science changes? What do we need to be
21 thinking about?

22 We obviously don't have a crystal

1 ball. We can't know for sure, but maybe
2 there's just a little bit of insight that you
3 guys can give us. So we want you to touch on
4 that a little bit tomorrow as well.

5 CO-CHAIR FELDMAN: Is the idea that
6 additional recommendations would grow out of
7 our discussion parking lot issues?

8 MS. JOHNSON: I think they could.
9 You know, and D.E.B., you might could help
10 more with this. But I would imagine HHS might
11 be interested in just ideas for things that
12 you may want to fund eventually.

13 MS. POTTER: HHS is interested in
14 what the stakeholders have to say. So if you
15 all think that something is really important
16 and that's not bubbling up then that should be
17 included in the report.

18 That's the purpose of all of this is
19 to hear from the stakeholders. So there's not
20 a right or a wrong.

21 CO-CHAIR PERFETTO: We also wanted to
22 give an opportunity to any of the people still

1 left behind us over here if there were any
2 comments or any issues that anyone wanted to
3 raise.

4 MS. JOHNSON: So I feel bad that
5 we're kind of filling in time. George, are
6 you on the line?

7 MR. VRADENBURG: I am.

8 CO-CHAIR PERFETTO: Great, well we've
9 been waiting for you. We've been stalling for
10 a few minutes while we've been waiting.

11 MR. VRADENBURG: Oh no, I apologize.
12 I had it at 5:15.

13 CO-CHAIR PERFETTO: Great. So let me
14 introduce George Vradenburg who is going to
15 give us a few comments. We had asked George
16 if he would be able to come today to join us
17 and he was not able to.

18 George is a tremendous advocate in
19 Alzheimer's disease and has been very active
20 in this area for a number of years. And leads
21 the Us Against Alzheimer's group as well as
22 other initiatives. So we thought it would be

1 nice to have someone like George give us some
2 of his thoughts on the direction for quality
3 and his experiences.

4 So George, I'm going to turn it over
5 to you.

6 MR. VRADENBURG: Well, thank you very
7 much. Was that Eleanor?

8 CO-CHAIR PERFETTO: It is.

9 MR. VRADENBURG: I want to say how
10 impressed I've been with Eleanor's leadership
11 in this area for now some period of time in
12 getting this work started, and getting it
13 focused, and getting it so comprehensive.
14 It's really a testimony to the importance of
15 leadership.

16 I want to thank you for taking this
17 call. I know how important this work is. In
18 my work where I'm on the Commission on Long-
19 term Care one of the things, one of the
20 critical elements that we to a person thought
21 was vitally important was the development of
22 some common assessment tools and an assessment

1 system across care settings, across the stage
2 of the disease, that could be implemented by
3 a workforce with multiple skill sets.

4 That was portable with the patient so
5 that as the patient moved through acute, post-
6 acute, home, or residential settings that the
7 assessment moved with the patient.

8 That it was patient-centric and
9 family-centric. That it included the
10 caregivers and the team that was charged with
11 the care for the individual no matter what the
12 setting.

13 And so we advocated that and it was
14 part of our Commission on Long-term Care work
15 that we thought that this is vitally
16 important. So that the work that you're doing
17 I know from experience across a number of
18 these efforts how important it is.

19 And really only three quick points
20 here. I do think it is -- this is obviously
21 my personal point of view coming from sort of
22 a patient advocate's or family advocate's

1 perspective.

2 But I think it is important that we
3 get clear what the objectives are of creating
4 a national quality system, assessment system.

5 It is not just a body of definitions
6 or professional guidance. It is a potential
7 tool to actually take a system that exists
8 today with whatever assessment across all
9 those things are in terms of the quality of
10 care being given to individuals and raise it
11 through time.

12 That is to say, to be able to assess
13 what the quality of care being delivered to
14 the patient populations we're concerned about.
15 And then to say through time what are the --
16 how is that system improving to improve the
17 quality of care as well as hopefully mitigate
18 the cost increase.

19 That means that the assessment system
20 has to have certain standards inside of it,
21 data-recording standards. It has to have a
22 certain format to it that can be used in

1 different care settings and by different kinds
2 of professionals.

3 It has to be capable of being -- the
4 data in those reports and assessments has to
5 be accessible in some national way.

6 And the people that are reporting, we
7 have to be able to compare the performance of
8 various elements in the system through time,
9 and across settings, and across stages of the
10 disease.

11 And therefore be able to hold
12 ourselves accountable for assuring through
13 time that the level of care that is occurring
14 throughout society is improving through time.
15 So point one, that we need some vision and
16 objectives for what we're trying to do with
17 the quality system.

18 The second is implementation. I've
19 heard people say that a vision without action
20 is a hallucination. So I do think we need a
21 system that can be implemented.

22 And I think that comes in two

1 dimensions. One is what I just said, that is
2 that we have a system with standardization and
3 reportability in it across these various
4 dimensions that I mentioned.

5 But it also has to do with who has to
6 change their behavior in order to get that
7 system actually put into place.

8 One of the things that comes across
9 pretty consistently inside the work that I do
10 with the NAPA Advisory Council on Alzheimer's
11 as well as the Commission on Long-term Care is
12 that the system is very, very complex with
13 multiple actors.

14 It has traditionally been viewed as a
15 medical system when we're now talking about
16 medical and social services which have never
17 been particularly well connected.

18 And so figuring out who it is that
19 has to change what in order to create
20 assessment tools that will be used by
21 different institutions and different
22 professional categories, and actually getting

1 it implemented. Or at least beginning to
2 describe and characterize the pathways to
3 getting it implemented I think is an important
4 element of trying to think through what we're
5 trying to achieve here.

6 Because a system that can't be
7 implemented and can't have consistent
8 reporting can't be held -- no one can be held
9 accountable and we won't get movement through
10 time in terms of the quality of care.

11 And the last point I'll make is that
12 the problem you're grappling with is occurring
13 -- is a problem being grappled with in other
14 countries in the world, particularly
15 industrialized countries now but increasingly
16 in low- and middle-income countries. Because
17 dementia is now not only global, two-thirds of
18 the cases are in low- and middle-income
19 countries.

20 So finding a system that can be
21 easily described, easily characterized and
22 where one can understand where the levers of

1 change can be and where it can be implemented
2 and implemented at relatively low cost is
3 going to be important to the world.

4 And so America can both lead here if
5 we can find a way to characterize, describe
6 the system and its implementation with clarity
7 and simplicity.

8 But it also can learn from what's
9 going on in other industrialized nations,
10 particularly those that have national health
11 systems, whether it be the European system or
12 the Asian systems, because they have fewer
13 levers to turn, but they also have the same
14 objectives.

15 What is the diagnosis rate for those
16 that are at risk or have the disease. What is
17 the most diagnostic pathway to treatment and
18 to care. Are care systems adequately
19 documented and implemented. And are patients
20 receiving the care that they need and deserve
21 and want, and customized and personalized in
22 a way that makes sense for them. And is that

1 improving the outcomes of the people that
2 we're all trying to serve.

3 So that is occurring in Europe now.
4 It's also occurring in major Asian countries
5 that are indeed grappling with the problem.
6 And so we can both learn and we can also
7 teach.

8 If we are able to characterize our
9 system in a way that is not complex and not
10 difficult to understand and if it is patient-
11 centric rather than system-centric so that in
12 fact it can be well understood by those that
13 we're trying to serve.

14 So, I thank you for the opportunity
15 to offer just a few comments. I hope that
16 they're relevant. I do not have the expertise
17 that you all have but I am relying very much
18 on your expertise to hopefully develop a
19 system that is -- that can over time both
20 measure and improve the care that are given to
21 people with dementia.

22 CO-CHAIR PERFETTO: George, do you

1 have a minute for any questions if anyone has
2 a question for you?

3 MR. VRADENBURG: Sure.

4 CO-CHAIR PERFETTO: Does anyone have
5 any questions? You know what, I think we wore
6 everyone out today, George. They're all
7 looking very tired.

8 (Laughter)

9 MR. VRADENBURG: There are a series
10 of convenings that are going on now in Europe
11 and then will occur in the United States this
12 fall and then Japan later in the year all of
13 which are going to try to develop this sort of
14 set of ways to measure the quality of care
15 that's delivered and received both by the
16 person with dementia as well as the caregiver.

17 So this is going to be a year of
18 learning to say the least on these care
19 systems and to determine where there are good
20 ideas that can be translated across national
21 boundaries and be able to implement some of
22 the commitments that the G8 nations have made

1 and now the OECD and 34 nations to deal with
2 this problem both as a problem of research and
3 new medicine development as well as care.

4 CO-CHAIR PERFETTO: George, thank you
5 very much for joining us. And hopefully the
6 report that will come out of this effort will
7 be very useful to those other initiatives that
8 are going on.

9 MR. VRADENBURG: Terrific. Thank you
10 very much.

11 CO-CHAIR PERFETTO: Thanks. Bye.

12 MR. VRADENBURG: Bye.

13 MS. MYERS: Operator, can we open the
14 line for any other public comments?

15 OPERATOR: At this time if you have a
16 comment please press *1 on your telephone.
17 There are no comments at this time.

18 MS. MYERS: Thank you.

19 MS. JOHNSON: Okay, I think we're
20 done for the day. So, go have some supper and
21 relax and we'll see you bright and early
22 tomorrow. I think we're starting at 8, is

1 that right?

2 MS. FELDMAN: Yes. The meeting will
3 start at 8. Breakfast is at 7:30. Please do
4 not come before 7:30 though because the
5 building will not be open. So, 7:30.

6 MEMBER COOLEY: Be back with you
7 then. Bye bye.

8 MS. FELDMAN: Thank you.

9 (Whereupon, the foregoing matter went
10 off the record at 5:24 p.m.)

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This is to certify that the foregoing transcript

In the matter of: Alzheimer's Disease and
Related Dementias Committee

Before: NQF

Date: 06-02-14

Place: Washington, DC

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