

NATIONAL QUALITY FORUM

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MEASURE APPLICATIONS PARTNERSHIP

DUAL ELIGIBLE BENEFICIARIES WORKGROUP

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THURSDAY

MARCH 30, 2017

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The Workgroup met at the National Quality
Forum, 9th Floor Conference Room, 1030 15th
Street, N.W., Washington, D.C., at 9:00 a.m.,
Jennie Chin Hansen and Michael Monson, Co-Chairs,
presiding.

PRESENT:

JENNIE CHIN HANSEN, RN, MS, FAAN, Workgroup Co-Chair, Subject Matter Expert

MICHAEL MONSON, MPP, Substitute Workgroup Co-Chair, Centene Corporation

CHRISTINE AGUIAR LYNCH, MPH, Association for Community Affiliated Health Plans

JOE BAKER, JD, Medicare Rights Center

RICHARD BRINGEWATT, SNP Alliance

GWENDOLEN BUHR, MD, MHS, Med, CMD, American Medical Directors Association

ALISON CUELLAR, PhD, Subject Matter Expert

WENDY FOX-GRAGE, MS, MPA AARP Public Policy Institute

JOY HAMMEL, PhD, OTR/L, FAOTA, American Occupational Therapy Association

ALINE HOLMES, DNP, MSN, RN, New Jersey Hospital Association

K. CHARLIE LAKIN, PhD, Subject Matter Expert

ALICE LIND, BSN, MPH, National Association of Medicaid Directors*

THOMAS H. LUTZOW, PhD, MBA, iCare

STACEY LYTTLE, MPH, CMS Medicare-Medicaid Coordination Office

D.E.B. POTTER, MS, Office of the Assistant Secretary for Planning and Evaluation

JENNIFER RAMONA, Homewatch CareGivers

KIMBERLY RASK, MD, PhD, Subject Matter Expert

E. CLARKE ROSS, DPA, Consortium for Citizens with Disabilities

JOAN LEVY ZLOTNIK, PhD, ACSW, National Association of Social Workers

NQF STAFF:

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 MADISON JUNG, Project Analyst
 DEBJANI MUKHERJEE, MPH, Senior Director
 ELISA MUNTHALI, MPH, Vice President, Quality
 Measurement
 ERIN O'ROURKE, Senior Director
 RACHEL ROILAND, MS, PhD, Senior Project Manager
 MARCIA WILSON, PhD, MBA, Senior Vice President,
 Quality Measurement

ALSO PRESENT:

BRIAN ABERY, MS, PhD, Coordinator of School-Age
 Services, Institute on Community
 Integration (ICI) & Adjunct Faculty,
 Institute on Child Development and School
 Psychology Programs, University of
 Minnesota*
 ELIZABETH FRENTZEL, MPH, Principal Research
 Scientist, American Institutes for
 Research*
 BETH JACKSON, PhD, Director, Truven Health
 Analytics*
 KAREN JOYNT, MD, MPH, Senior Advisor to the
 Deputy Assistant Secretary for Planning
 and Evaluation, Office of the Assistant
 Secretary for Planning and Evaluation*
 KERRY LIDA, PhD, Health Insurance Specialist,
 Center for Medicare and Medicaid Services,
 HHS*
 CORETTA MALLERY, PhD, Principal Researcher,
 American Institutes for Research*
 SUSAN RAETZMAN, MSPH, Senior Research Leader,
 Behavioral Health and Quality Research,
 Analytic Consulting and Research Services,
 Truven Health Analytics*
 RENATA TICHA, PhD, Research Associate; Director
 of Global Resource Center for Inclusive
 Education, Institute on Community
 Integration, University of Minnesota*

ALSO PRESENT:

ROBIN YABROFF, MBA, PhD, Analyst, Office of
Health Policy, Office of the Assistant
Secretary for Planning and Evaluation*

RACHAEL ZUCKERMAN, PhD, Office of the Assistant
Secretary for Planning and Evaluation*

* present by teleconference

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

2 (9:06 a.m.)

3 CO-CHAIR MONSON: Thank you,
4 everybody. So, we are going to get going. I
5 think the goal is to try to start early so that
6 we will start on -- well, actually we're starting
7 late. The goal is to end early so people can
8 catch flights and things of that nature.

9 You know, as I said yesterday, we had
10 a really productive day yesterday. And again
11 appreciate everybody's continued engagement as we
12 come down to this being our last formal meeting,
13 although I'm sure that there will be some new
14 incarnation of this group. That was to put
15 pressure on Marcia to make sure that happens.

16 So, but we've got actually a lot of
17 presentations today. I think these are things
18 that we've all wanted to see and we've talked
19 about. We're going to see Charlie's team from
20 Minnesota. We're going to see the HCBS
21 experience of care survey, the new CAHPS survey.
22 We're going to hear about social determinants of

1 health.

2 So, without further ado, I think we're
3 going to hand it over to Kate.

4 MS. BUCHANAN: Hi, everyone. My name
5 is Kate Buchanan. I am a project manager here
6 with NQF. And I just wanted to review the
7 changes that we made to the family of measures.

8 So, the workgroup voted to remove four
9 measures: the 0043, pneumococcal vaccine status
10 for older adults; 0682, the percent of residents
11 or patients assessed and appropriately given the
12 pneumococcal vaccine, short stay.

13 And the workgroup noted that they were
14 concerned about the removal of these measures
15 because of the importance of the vaccines,
16 measuring the vaccines. But they discussed that
17 there may be changing in the standards of what is
18 appropriate care, so that they will be on the
19 look out for measures, new measures dealing with
20 pneumococcal vaccination.

21 The other two measures that the
22 workgroup voted to remove are 0558, HBIPS-7, the

1 Post-Discharge Continuing Care Transmitted to the
2 Next Level of Care Provider Upon Discharge; and
3 0557, HBIPS-6, Post-Discharge Continuing Care
4 Plan Created.

5 And so the workgroup discussed that
6 originally these measures had been designed
7 specifically for a psychiatric population, but
8 have since been expanded. Additionally, we
9 discussed the fact that there are additional
10 post-discharge measures within the family, so we
11 decided not to replace any of them.

12 So, the workgroup voted to include
13 four new measures into the family. And there
14 were some overall comments in the workgroup on
15 these measures. They noted while many of these
16 measures are not tested specifically in a duals
17 population, there was some concern over this.
18 Additionally, there was some concern about the
19 risk stratification of each measure. But the
20 workgroup said, even though these measures are
21 not perfectly suited for the population, they can
22 improve the quality of care that dually eligible

1 individuals receive and so they should be
2 included in the family,.

3 So, with that in mind, the workgroup
4 decided to include NQF 3086, Population Level HIV
5 Viral Load Suppression. And the workgroup noted
6 that this intermediate outcome measure addresses
7 an important aspect of care for individuals with
8 HIV, a significant portion of which are dually
9 eligible.

10 The workgroup also included NQF 2858,
11 Discharge to Community. And the workgroup said
12 that this measure focus, keeping people in the
13 community, aligns precisely with the workgroup's
14 charge.

15 The other two measures that the
16 workgroup voted to include were NQF 2775,
17 Functional Change: Change in Motor Score for
18 Skilled Nursing Facilities. And the workgroup
19 members really emphasized the importance of
20 functional measures and decided to include it in
21 the family.

22 The last measure, NQF 2776, Functional

1 Change: Change in Motor Skill in the Long Term
2 Acute Facilities. So, there was some discussion
3 around the ability to measure the short-term
4 rehabilitation in patients, but the workgroup
5 discussed the importance of functional change in
6 any care setting, including LTACs, and decided to
7 include it in the family.

8 There were three new endorsed measures
9 the workgroup decided not to include. And those
10 are NQF 2614, CoreQ: Short Stay Discharge
11 Measure; NQF 2615, CoreQ: Long-Stay Resident
12 Measure; and NQF 2616, CoreQ: Long-Stay Family
13 Measure.

14 And the workgroup wanted to really
15 emphasize that PROs and family-reported outcomes
16 are incredibly important to include in the
17 family, and that there are few opportunities for
18 individuals and their family members to provide
19 feedback on the institutional care they receive.
20 Although, with this in mind, there was incredible
21 concern about the validity of the responses.
22 They were concerned that the measures will be

1 skewed towards a positive outcome for the
2 facility.

3 And with regards to NQF 2615 and NQF
4 2616, workgroup members were not sure that the
5 questionnaires were accessible to individuals
6 with literacy, health literacy, and cognitive
7 function impairments, but that they really wanted
8 to note in the report the importance of PRO in
9 family-reported outcome measures.

10 So, with that, I want to see if there
11 are any questions or comments?

12 (No response.)

13 MS. BUCHANAN: Seeing none, I will
14 turn it over to our first presentation. And I
15 want to briefly introduce our presenters.

16 Karen Joynt is a cardiologist at
17 Brigham and Women's Hospital. Rachael Zuckerman
18 and Robin Yabroff are analysts at ASPE.

19 Dr. Joynt led the ASPE team that
20 completed the first report to Congress on social
21 risk factors and Medicare payment policy. And
22 Dr. Yabroff is leading the team currently working

1 on the second report.

2 And I just want to make sure that we
3 are able to hear Karen, Rachael, and Robin?

4 DR. JOYNT: This is Karen. Can you
5 hear me?

6 MS. BUCHANAN: Yes.

7 DR. YABROFF: This is Robin.

8 MS. BUCHANAN: Great.

9 DR. ZUCKERMAN: And this is Rachael.

10 MS. BUCHANAN: Wonderful. And if you
11 wouldn't mind, just when it's time to move to the
12 next slide, just say "next" and we'll move the
13 slides for you.

14 And with that, I'll hand it off.

15 DR. JOYNT: Great. Thank you so much
16 for having us this morning. We're really excited
17 to get to talk with you. And from even the
18 little bit of your meeting that we just got to
19 sit in on, I think we're going to learn a lot
20 from what you can tell us about emerging measures
21 as we get through our presentation here. So
22 we're going to try to keep the presentation

1 pretty brief, and then we'll very much look
2 forward to your feedback.

3 I'm going to go through a brief
4 overview of our first report. And then Robin
5 will take the baton and go through our plans for
6 the second part of the study. And so, hopefully,
7 we'll get a chance to update you on where we have
8 been and where we're going, and get your feedback
9 on where we should be headed. So we really
10 appreciate your time.

11 Next slide, please.

12 Okay. So, as you all know, we worked
13 on this report because of the IMPACT Act, the
14 Improving Medicare Post-Acute Care Transformation
15 Act. ASPE was charged with addressing the issues
16 of social risk factors which, as you certainly
17 all know, play a major role in health. And as
18 higher levels of provider accountability move
19 across nearly all Medicare settings, the issue of
20 social risk and value-based payment really have
21 started to intersect.

22 And so the IMPACT Act mandated

1 essentially four pieces of work. And we'll talk
2 about almost all of them today.

3 So, first, a study of the impact of
4 socioeconomic status, which we've reframed as
5 social risk, on quality and resource use in
6 Medicare using existing socioeconomic data, which
7 is what I'll be talking about first.

8 Second, a study of the impact of
9 socioeconomic status on quality and resource use
10 in Medicare using measures from new data sources,
11 like education, health literacy, et cetera. And
12 that's what Robin's going to be talking about.

13 Third, a qualitative analysis of data
14 sources and context around defining SES. And for
15 that we had the National Academy of Medicine do a
16 wonderful set of reports sort of doing a deeper
17 dive into the background and context around a lot
18 of these issues which we'd refer you to as well.

19 And then a final report with
20 recommendations due in 2019.

21 Next slide, please. So, the way that
22 the report is set up -- I don't know how many of

1 you had a chance to look through it -- but the
2 intent was to set it up such that once you sort
3 of knew what one chapter was going to look like,
4 the rest would follow a similar setup. So I'll
5 talk through sort of a generic setup here.

6 We selected a set of social risk
7 factors. The predominant one ended up being dual
8 enrollment in Medicare and Medicaid, which is
9 convenient for this committee. But it wasn't
10 selected just randomly. It was selected because
11 in our analyses it was really consistently the
12 most powerful social risk factor that we
13 examined. So many of these other factors:
14 residents in low income areas, black race,
15 Hispanic ethnicity, rural residents, and
16 disability were important factors, but fairly
17 consistently the dual enrollment dominated. So
18 that's what we'll really focus on.

19 We looked across the Medicare payment
20 programs that are currently in place that
21 incorporate resource use and quality measures.
22 And if your screen is as small as mine, I suspect

1 those are very, very small boxes. But
2 essentially there's three value-based payment
3 programs in the hospital setting.

4 In the ambulatory setting we looked at
5 Medicare Advantage, MSSP, and the value-based
6 payment modifier which will sunset and turn into
7 MIPS in a few years.

8 And then facility-based, so dialysis
9 facilities, nursing facilities, and home health
10 agencies. Those last two we really just did some
11 exploratory analyses because those programs are
12 still in the sort of getting-up-and-running
13 stage.

14 Next slide, please.

15 So, we really had two main findings.
16 There's lots and lots of little findings. But I
17 think one thing that was impressed upon us when
18 we put it all together was really that there were
19 patterns across the different settings. And so
20 we found both patient and provider effects. So
21 I'll talk through each of those.

22 So, first, we found that beneficiaries

1 with social risk factors had worse outcomes of
2 quality measures, regardless of the providers
3 they saw. And dual enrollment status was the
4 most powerful predictor of poor outcomes.

5 So, even when we ran models in which
6 we were only comparing folks within the same
7 practice or hospital or contract, there really
8 was a significant and pretty consistent effect,
9 especially of dual status, in terms of
10 performance on quality measures across the board,
11 not only normally process measures but outcome
12 measures and resource use measures.

13 However, of course, the story is more
14 complicated than that. And our second finding
15 was that there was also a provider effect. So,
16 providers that disproportionately served
17 beneficiaries with social risk factors tended to
18 have worse performance on quality measures, even
19 after accounting for their beneficiary mix. And
20 we can talk about why that might be the case, but
21 it was essentially, instead of a simple finding,
22 we ended up with a more complicated one, that we

1 see both a beneficiary effect and a provider
2 effect.

3 And the consequence of these effects
4 is that under all five value-based purchasing
5 programs in which penalties are currently
6 assessed, these providers had somewhat higher
7 penalties than the providers serving fewer
8 beneficiaries with social risk factors.

9 Next slide, please.

10 So, here's an example. And the
11 details here don't really matter, but I'm just
12 going to try to walk you through the picture to
13 sort of get a visual for the type of findings.

14 So this is looking at quality measures
15 within the Medicare Advantage program, which are
16 a range of measures from process to outcome. And
17 you can see here all the red bars indicate where
18 dual enrollees had lower odds of meeting the
19 measure. So, for diabetes, for example, blood
20 sugar control, up at the top there, they had 32
21 percent lower odds of meeting the measure. As
22 you go down, those effects get smaller. So, very

1 small differences, for example, in kidney
2 disease, the other end of the red bars, at only 7
3 percent.

4 And as you get down to measuring
5 physical activity and BMI assessment there was no
6 difference. And for whatever reason, reducing
7 risk of falling, that quality measure was much
8 more often met in dually enrolled individuals.
9 But, essentially, we saw a reasonably consistent
10 pattern of a sort of a small to moderate dual
11 effect across a wide range of measures.

12 Next slide, please. What that
13 translated into was that when we had Medicare
14 Advantage contracts with a high proportion of
15 duals, they were much, much less likely to meet
16 the four-star bonus threshold, which is once you
17 get four stars you're eligible for a 5 percent
18 bonus. So there's sort of a natural cut-off at
19 four stars built into the program.

20 And you can see here that, on the left
21 side of the screen, 72 percent of contracts with
22 the lowest proportion of dually enrolled

1 individuals were able to meet four stars,
2 compared with only 26 percent of those in the
3 highest quintile of dual enrollees.

4 Next slide, please. Now, of course,
5 this group is probably one for which this slide
6 will be almost self-evident, saying that there
7 are differences doesn't answer the whys of why
8 there are differences. And, certainly, one
9 solution will not address all causes.

10 So I think we realized in doing this
11 work that it actually isn't just about whether or
12 not you adjust the measures, because so many
13 things are feeding into these patterns that we
14 see that we wanted to sort of take the
15 opportunity and expand the discussion to think
16 through what these factors are and how we might
17 sort of start a conversation about the ways that
18 measurement and quality programs actually
19 influence these outcomes.

20 Certainly, on the bottom left, quality
21 of care, you know, we did find that providers
22 serving a high proportion of duals seem to

1 provide lower quality.

2 We also know that duals have higher
3 medical risk that's measured, which is
4 incorporated into some quality measures and not
5 into others. We know that they have higher
6 medical risk that's unmeasured, things like
7 functional status. And so I loved seeing the
8 conversation right before we started about how to
9 measure things like that.

10 We also know that duals have lower
11 levels of social support and tend to live in more
12 areas with higher levels of neighborhood
13 deprivation, for example.

14 We know that there are issues with
15 medication compliance and lifestyle, things like
16 tobacco use among low income beneficiaries, that
17 may contribute to outcome. And we certainly know
18 that in life in general, many individuals with
19 social risk factors face bias. And all of these
20 things can feed into the ways that worse outcomes
21 manifest in these groups.

22 Next slide, please. So we came up

1 with three sort of strategic goals in thinking
2 about how Medicare and HHS might really start to
3 think about how social risk interacts with the
4 value-based payment programs. And these are all
5 considerations for policymakers and clinical
6 leaders and other folks to sort of get started
7 on.

8 So, the first big strategy is to
9 measure and report quality for beneficiaries with
10 social risk factors. The first bullet point
11 under that is essentially saying that we need to
12 have adequate data collection and statistical
13 techniques to allow us to measure and report
14 performance for these groups about which we're
15 particularly worried, so that we can see and
16 monitor and track progress into reducing
17 disparities.

18 The second bullet point talks about
19 introducing health equity measures or domains
20 into existing payment programs. And we don't
21 know what those would look like, and we certainly
22 look forward to your thoughts about that. But

1 not only measuring performance but actually
2 measuring equity, and publicizing those
3 measurements through programs, would be one way
4 to bring this more front and center.

5 And, third, prospectively monitoring
6 the Medicare payment program, and as new payment
7 programs roll out, understanding their impact on
8 the providers that disproportionately serve
9 beneficiaries with social risk factors feels like
10 an important thing as well.

11 Next slide, please. The second big
12 strategic bucket is to set high, fair quality
13 standards for all beneficiaries, which is sort of
14 a shorthand for saying that we don't have one
15 recommendation about whether or not measures
16 should be adjusted or not. Each measure is
17 different. And so each measure should be
18 examined to determine if adjustment for social
19 risk factors is appropriate, which is exactly
20 what the NQF has been undertaking during its
21 trial period.

22 And really, I think, for us at HHS,

1 and also for folks who have been involved in that
2 trial period, it's been very illustrative to see
3 just how complex and varied these relationships
4 are.

5 The second part here is also germane
6 to the conversation you all were just having,
7 which is that we would encourage the measure
8 development community to continue to study
9 measures to determine whether differences in
10 health status may underlie some of these observed
11 relationships. So, things like functional
12 status, which are hard to measure, but we know
13 are important. Things like disability or
14 frailty. Ways that could better pick up some of
15 the differences between patients with social risk
16 factors and those without, that we might be able
17 to pick up using, for example, claims data,
18 functional status data, or patient-reported
19 outcome measures.

20 Next slide, please.

21 And, finally, the third strategic
22 heading here is to reward and support better

1 outcomes for beneficiaries with social risk
2 factors. And so the first bullet talks about
3 creating targeted financial incentives within
4 value-based purchasing programs to reward
5 achievement of high quality and good outcomes or
6 significant improvement among beneficiaries with
7 social risk factors. And this would be a way to
8 try to offset some of the perceived risk of
9 caring for these folks under value-based payment
10 programs.

11 Bullets two and three really talk
12 about targeted support, technical assistance, and
13 the potential for demonstrations or models that
14 really focus on the providers that serve
15 beneficiaries who are at risk, as well as the
16 beneficiaries themselves. How can we really
17 innovate in the ways that we know we should be in
18 terms of things like integration of behavioral
19 health, or care coordination, or linking with
20 social services, or whatever people think are the
21 best ways to innovate around this population.
22 Are there ways that we could perhaps encourage

1 that innovation to really start to change
2 disparities?

3 And then, finally, additional research
4 on the cost of providing -- or the cost of
5 achieving good outcomes for beneficiaries with
6 social risk factors, to think about what sort of
7 resources it might take and how those could be
8 deployed to try to address these issues.

9 So that's a very fast, high level
10 overview of a big report. But hopefully it gives
11 you a flavor for sort of the themes that we've
12 tried to hit. And we can either pause there or
13 we can move on to Study B and do questions at the
14 end. Do you all have a preference?

15 CO-CHAIR MONSON: I think we have some
16 questions now. So, if that's okay, we'll start
17 with that.

18 MEMBER CUELLAR: Yeah, if you don't
19 mind, could you give us an example of Number 1,
20 your targeted financial incentive? How would you
21 envision that?

22 DR. JOYNT: Sure. Yeah, I can give

1 two examples, actually, of existing things in
2 Medicare.

3 So, the first is what the Medicare
4 Advantage program implemented on a trial basis
5 this year, which is essentially a small
6 adjustment given to contracts based on their
7 proportion of dual and disabled individuals. So
8 they did a fairly complex modeling approach,
9 found what the differences were on performance,
10 and then turned that back into a bit of a bonus
11 for contracts with a high proportion of dual and
12 disabled individuals that fed into the Star
13 system.

14 Another example, one that we talk
15 about more in the report, is actually a current
16 bonus opportunity in the physician value-based
17 payment modifier program. And that program has
18 only been in -- I guess it's paying in its second
19 year now, so it's pretty new. But in the first
20 year the setup was such that if you are a low-
21 cost/high quality or average cost/high quality
22 performer you're eligible for a bonus. And the

1 flip side, if you're high cost and low quality
2 you're eligible for a penalty or a negative
3 payment adjustment.

4 But there's also an additional bonus
5 opportunity, which is that if you earn a bonus,
6 you can get a double bonus if you happen to have
7 a very sick patient population. So, if your
8 patients are in the highest quartile of medical
9 risk, you have an additional bonus opportunity.
10 That's not social risk, but it was an example
11 within the current Medicare programs where there
12 has been creative thinking about how, you know,
13 bonuses or adjustments could be used based on the
14 patient population that folks are treating.

15 MEMBER CUELLAR: So, following up, did
16 you also discuss stratifying in terms of the
17 reporting of these outcomes so that one could at
18 least see where these disparities are?

19 DR. JOYNT: Yeah. So that was our,
20 it's the first bullet under Number 1. And we
21 don't use the word "stratifying" because it
22 caused a lot of confusion actually.

1 There's a couple ways you could
2 stratify. You could stratify by practices or by
3 hospital. So, you know, the 21st Century Cures
4 Act includes language stratifying hospitals under
5 the Hospital Readmissions Reduction Program.

6 What we were really talking about was
7 I think what you're bringing up, which is almost
8 like subgroup reporting. It's stratifying the
9 patients and saying how can we develop the data
10 capabilities and statistical capabilities to be
11 able to say, "Here's how our dually enrolled
12 population is performing on cancer screening.
13 Here's how our Hispanic population is performing
14 on diabetes control." Whatever the issue may be.

15 A lot of the measures right now,
16 certainly not some of the big ones like
17 admissions or readmissions, but many of the
18 quality measures that are a sample of patients,
19 the sample sizes are very small when you get down
20 to subgroups within practices or contracts or
21 hospitals. So it's not even feasible with
22 current data to sort of across-the-board make

1 that happen.

2 So it will require some thought both
3 on data collection, burden of data collection, of
4 course, and also on the statistical techniques to
5 be able to do that. But, yeah, our intent was to
6 sort of spark that conversation with that bullet
7 point.

8 MEMBER ROSS: Hi. This is Clarke
9 Ross. In 2013 and '14, this workgroup spent two
10 years looking at four major subpopulations in the
11 duals population. And maybe D.E.B. or the staff
12 or Jennie or somebody could remind me precisely
13 what the four subgroups were. But my question
14 was, if you examine those reports, you considered
15 stratifying your analysis based on these four
16 different population dynamics. Because at the
17 time we thought it was really important to
18 differentiate 30-year-old people with severe
19 intellectual disabilities, 72-year-old so-called
20 frail, elderly folks, to get a better picture of
21 the duals population.

22 So, my question is, were you aware of

1 those, of our effort to look at those four
2 populations, and what were your thoughts in
3 building them into your analysis?

4 DR. JOYNT: Yeah, that's a great
5 point. I cannot speak to whether or not we
6 reviewed your work or not. I know we looked at a
7 lot of stuff. But I will certainly look back and
8 see.

9 I guess the fairest answer is "sort
10 of." So, I suspect what you're talking about is
11 the dual, non-aged, dual-aged, and then the folks
12 with comorbid disability as the initial --
13 original reason for Medicare entitlement. And we
14 did some of that.

15 In some of the measures, and some of
16 the programs, that disability variable was
17 actually built in. And in many of the measures,
18 the under-65s are excluded. So in our report,
19 it's a bit of a grab bag, actually, exactly who's
20 in what, because of the ways that the different
21 measures are built.

22 You know, part of something that we

1 touch on in the report, though I didn't put it in
2 the slides here, is that there's really not
3 probably enough understanding of the under-65s,
4 in part because they're excluded from many of the
5 quality measures because they're thought to be a
6 different population. But that's probably where
7 a lot of risk lies.

8 Another thing we looked at, and I'm
9 not sure if this is one of the groups that you
10 were looking at, but it's full versus partial
11 duals. And we found that the partials looked
12 much more like the fulls than they looked like
13 the nons, if that makes sense. So when we looked
14 at performance on quality measures, the partial
15 duals were perhaps a little better than the full
16 duals, but they were not -- they looked more
17 similar to the full duals than they did to the
18 non-duals.

19 And I think that's because when you're
20 talking about full or partial duals you're still
21 talking about pretty low income. And so we did
22 lump those two groups together after looking at

1 those analyses.

2 But if you could forward along any of
3 that prior information we'd love to review it as
4 we think through the second part of the study.

5 CO-CHAIR CHIN HANSEN: Right. Just to
6 fill in the other two groups, other than what
7 Clarke mentioned, were people who were duals and
8 substance abuse category, as well as severe
9 mental illness category. So, those comprised the
10 four clusters that we looked at for a couple of
11 years as a backdrop.

12 DR. JOYNT: Got it. We'd love to see
13 that and think about it as we move into the
14 second part of the study. That would be great if
15 someone could send that along or direct us to
16 where it is.

17 CO-CHAIR MONSON: Tom.

18 MEMBER LUTZOW: Yeah, this is Tom
19 Lutzow with iCare. We're a managed health plan.

20 The IMPACT Act is quite a
21 breakthrough, I think. But, you know, just
22 looking back, I wish Part C plans had somehow

1 been included strategically, because it is a
2 measure of interest to plans. It features
3 interconnectivity, encourages electronic
4 interconnectivity between key providers, all
5 joined around a common end. And it would have
6 been helpful if somehow Part C plans were
7 included. But that's water over the dam.

8 The observation that we have, we're
9 spending a lot of time on transitions of care and
10 readmissions with our key systems. And of course
11 we're concerned about 30-day readmits. But if
12 you go out to 60 and 90, with some segments of
13 the population we're seeing, you know, 24, even
14 30 percent readmission within 30 days. But if we
15 go out 90 days, it's more like 50, 60 percent.

16 And so, you know, I think a longer
17 perspective is probably important from a
18 recovery, quality of life, savings perspective,
19 all the Triple Aim stuff. And it probably
20 starts, in our case it does start with a
21 readmission risk assessment in the hospital.
22 Those that score 11 or higher on the scale are

1 followed to home, if they let us follow to home.
2 And a good percentage don't want us in the house.
3 So, you know, there's that difficultly too.

4 But, you know, just an observation
5 that the real impact here may be at the 60-90 day
6 level than at the 30-day level.

7 DR. JOYNT: I think that's a terrific
8 thought. And I love your comment about the home
9 visits as well. This is, you know, I think in
10 the hospital setting people worry about how long
11 you get out that's away from sort of control of
12 the hospital.

13 In the contract or the ACO or the
14 primary care setting maybe it's the opposite,
15 maybe we think about admissions instead of
16 readmissions as sort of the, I don't know, locus
17 of control or something. So your point is very
18 well taken. Thank you.

19 MEMBER BRINGEWATT: Yes. This is Rich
20 Bringewatt with the SNP Alliance.

21 As you probably know, this is a
22 particularly important issue for our

1 organization, and a particularly important issue
2 for this workgroup. So, you know, really
3 appreciate all you've done in this area.

4 A couple of questions relative to the
5 research you did do, thinking about next steps in
6 particular. There's some discussion as to
7 whether, in terms of performance reporting, the
8 best alternative is to look at sub-populations to
9 compare apples to apples, so that if there is a
10 reporting public comparison of how plans perform
11 on Stars, you look at certain kind of SNPs versus
12 other certain kinds of SNPs, as opposed to SNPs
13 versus MMPs as a reporting process.

14 Another kind of general approach is to
15 do risk adjustment on the different performance
16 measurement. And the assumption is, if you do
17 risk adjustment, if you adjust for social
18 determinants of health on those performance
19 measures, then you can do a proper comparison
20 before, because it's adjusted for.

21 Seems to me like that probably is
22 going to take a while in order to really get at

1 that, as well as it's dependent upon kind of
2 findings of the stewards of the measures. And so
3 a second part of that question of comparison
4 groups versus risk adjustment is, do you have any
5 recommendations to stewards of measures for how
6 they account for social risk factors, and other
7 factors, you know, such as care complexity and
8 its interventions?

9 But the methodology for addressing
10 social risk factors, it seems to me, is as
11 important as doing it. And if you don't fully
12 take into account, particularly, as an example,
13 neighborhoods and going down to 9-digit ZIP
14 level, stay at a higher level where you have a
15 mix of different income groups, you get different
16 results.

17 So, comment on those two questions.

18 DR. JOYNT: I wish we could hand over
19 part of our second report to you to write,
20 because those are all the things that we've been
21 grappling with, too. I don't think there is a
22 perfect solution, unfortunately. There's pros

1 and cons to adjusting, there's pros and cons to
2 stratification. And so part of the next couple
3 years is going to be working with various groups
4 to try to figure out in what situations is each
5 approach best suited.

6 And, you know, actually if you look in
7 the Medicare Advantage chapter in the report, it
8 looks like, if you look at the relationship
9 between proportion, dual, and performance, it
10 looked a little bit like a Nike swoosh in that
11 the contracts that actually had the highest, the
12 very highest proportion of duals tended to do a
13 little bit better for the duals. So there, you
14 know, there is something to be said for a group
15 that looks more alike in which folks are
16 actually, I think probably -- I don't know this
17 for sure -- but probably investing in the types
18 of things that can really start to make a
19 difference in those populations.

20 So there's, you know, pockets of
21 innovation and things that we need to learn from.
22 So I don't think that adjusting everything or

1 stratifying everything is actually the right
2 approach across the board. And that's the tricky
3 part that we, and, frankly, CMS who has to think
4 about these things in a much more implementation-
5 friendly standpoint than we do, will really think
6 through a lot of in the next couple years.

7 MEMBER BRINGEWATT: If I could still
8 do a brief follow-up on that, and that is
9 guidelines as it relates to stewards or
10 developers of measures in looking at the effects
11 of social determinants of health or social risk
12 factors on their measure. And that's been an
13 important role of the National Quality Forum here
14 in telling performance measure stewards that they
15 need to make this, you know, they need to do the
16 analysis.

17 But there's still a question as to how
18 they do the analysis and in terms of what the
19 results might be. And wondered whether you have
20 any comments relative to that.

21 DR. JOYNT: You know, in terms of the
22 measure development, we have largely left that to

1 NQF. It's been a pretty spectacular effort to
2 corral all of that information and get it into
3 this trial period. So we have not been -- we
4 have not given particular guidance on how that
5 should look.

6 I think as that trial period continues
7 and concludes and decisions are made and all that
8 sort of thing, we will be following that very
9 closely. And it's terrific work, and we would
10 certainly be remiss if we didn't take a very
11 close look at the results of all of that work
12 that was done when we think through where we
13 should be headed.

14 MEMBER BRINGEWATT: Are these slides
15 available?

16 DR. JOYNT: They're not, but the
17 report is. So all of this comes pretty directly
18 from the executive summary of the report, which
19 is the first, I don't know, 15 pages or
20 something. And then the last maybe 17 pages have
21 a similar thing but with all the detail in terms
22 of there's tables with the detailed findings for

1 each program in the last chapter. So, the first
2 and the last chapter will look very, very similar
3 to these slides.

4 MEMBER BRINGEWATT: It's just a nice
5 composite of information as the PowerPoint is
6 presented, and was wondering whether that was
7 available.

8 DR. JOYNT: Not currently.

9 MEMBER PARKER: I don't have a
10 question for the report exactly, but I wondered
11 if someone would just clarify again for me the
12 categories, the subgroups that NQF developed in
13 the MAP group. Because, Clarke, when you said a
14 72-year-old frail elderly, that's a real odd duck
15 these days. You know, that's a real severe
16 thing, because they're not so much that.

17 And so I think in terms of the old,
18 the older old, which, you know, average is over
19 age 85 usually. And then, you know, then there's
20 the under-65 people with disabilities. And then
21 some of those have IDD, and some of them have
22 SPMI and substance abuse, usually. So think of

1 those four groups.

2 So I don't know what the groups were
3 that you guys were thinking of, or that you guys
4 came up with. It would be helpful to know that
5 just to put this in context of, like, what Rich
6 is talking about, you know, and what this report
7 is talking about.

8 MEMBER POTTER: I just had a follow-up
9 on Pam's. In my memory, I thought one of the
10 groups was the cognitively impaired. So, maybe
11 we should go back and dig up the report and
12 remind us all.

13 MEMBER PARKER: Yeah, it would be
14 helpful to have that.

15 CO-CHAIR MONSON: So, do you have a
16 burning question, Joy, or can we move on to the
17 next presentation? Because they have another
18 full presentation we've got thirty minutes left.
19 But you get to go first, then, after the
20 presentation.

21 All right, we're turning it back to
22 our friends from ASPE to continue.

1 DR. JOYNT: Great. Robin, do you want
2 to run with Study B?

3 DR. YABROFF: Sure. Thanks, Karen.
4 And also thanks, everyone, for these really great
5 questions.

6 I also want to reiterate before I
7 start that we are very, very interested in your
8 input and feedback. And what I'm going to be
9 presenting is where we are to-date. We are in
10 the middle of moving a lot of the projects
11 forward related to what we call Study B. So your
12 input's going to be really helpful.

13 So if we could have the next slide,
14 please.

15 So, just to recap, as Karen said
16 earlier, across a broad set of measures and
17 programs we found that beneficiaries with social
18 risk factors tend to have poorer health outcomes
19 regardless of the providers that they see. And
20 that also that providers serving as beneficiaries
21 tend to have poorer performance, regardless of
22 the patients they serve. And they are also more

1 likely to be penalized.

2 Again, as Karen said, we don't really
3 know why these patterns exist. It could be that
4 beneficiaries have poor outcomes because they
5 have high levels of medical risk. They could
6 have worse living environments, greater
7 challenges in adherence and lifestyle, or they
8 may experience bias and discrimination.

9 Importantly, providers may also have
10 poorer performance because they have fewer
11 resources. They may also have more challenging
12 clinical workloads, lower levels of community
13 support, or worse quality. And many of these
14 factors with both beneficiaries and providers are
15 not easily measured with currently available
16 data.

17 So this is what really where we're
18 going to try and dig down a bit for Study B.
19 If I could have the next slide, please.

20 So, just to give you a quick overview
21 of our plans for Study B, we plan to build on the
22 first report to Congress framework, which Karen

1 described, where we evaluate risk factors and
2 their effects on beneficiary outcomes and
3 provider performance by program. We're going to
4 use a conceptual framework and recommendations
5 from a series of National Academy's reports. And
6 this picture here is the summary report:
7 Accounting for Social Risk in Medicare Payment.

8 We're going to be exploring new
9 measures of social risk and evaluate both medical
10 and social risk factors that are prevalent in
11 dually eligible beneficiaries. And then,
12 finally, examine program impacts and policy
13 solutions.

14 If I could have the next slide,
15 please. So, this slide shows the cover of the
16 first report that was produced by the National
17 Academy: Social Risk Factors in Medicare Payment.

18 And they identified five main social
19 risk factors, the first being socioeconomic
20 position: things like poverty, education, health
21 insurance; race, ethnicity, cultural context;
22 gender and gender identity; social relationships,

1 things like marital and partnership status,
2 living alone, instrumental social support;
3 residential and community context, and that's
4 where things like neighborhood deprivation or
5 high levels of inequality come into play.

6 They also identified a related factor:
7 health literacy. And it was mentioned in the
8 request for a report, but they didn't identify it
9 as a social risk factor per se.

10 And then, finally, the National
11 Academy identified disability more as a product
12 of social risk and health conditions, but they
13 did not define it as a social risk per se.

14 So if I can move on to the next slide.
15 So, the fourth report in the National Academy's
16 reports had recommendations for new data sources
17 that we could evaluate for evaluating and
18 measuring social risk. Some of those data
19 sources identified include surveys that can be
20 linked to Medicare claims data. The Medicare
21 Current Beneficiary Survey, the MCBS, is an
22 annual panel survey and includes about 15,000

1 Medicare beneficiaries. And then there's also
2 the American Community Survey.

3 And our plan is to link the American
4 Community Survey at the individual level so we
5 will have different levels of aggregation.
6 Typically, ACS data are used at the area like the
7 census block or census block group level, but
8 we'll also have the individual level through this
9 linkage. That has about 600,000 Medicare
10 beneficiaries per year.

11 So, although both types of surveys
12 have very rich data on social risk, the sample
13 sizes in these surveys are going to limit the
14 scope of the analyses that we can do.

15 Next slide, please.

16 So, we are going to be exploring the
17 measures of social risk, as I said, using survey
18 data-based projects with the MCBS and the
19 American Community Survey. And our goals in
20 these analyses will be to assess which social
21 risk factors are the strongest predictors of poor
22 outcomes, to explore interrelationships between

1 individual and community measures of social risk,
2 and also beneficiary outcomes, and then determine
3 how these different risk factors influence
4 provider performance.

5 The next slide, please.

6 We also have other projects that we
7 plan which will evaluate medical or social risk
8 factors that are more prevalent in dually
9 eligible beneficiaries. And here we're thinking
10 about things like frailty and disability, using
11 claims data-based projects, with a much larger
12 sample, to look at existing claims-based
13 measures, such as readmissions, admissions, and
14 costs.

15 And the goals here will be to identify
16 and validate new measures of medical risk
17 factors, assess relationships with social risk
18 factors, assess relationships with beneficiary
19 outcomes, and then also evaluate the influence of
20 these risk factors on provider performance.

21 Next slide, please.

22 So, with that, I would like to open it

1 up again to both discussions and questions. I've
2 listed, or we've listed our mailbox, if you have
3 any ideas that you would like to share or if the
4 discussion doesn't allow a full -- you know, we
5 don't have an opportunity to ask additional
6 questions. This is a really good way to contact
7 us. So it's aspeimpactstudy@hhs.gov.

8 So, with that, if anyone has questions
9 or comments, we're really interested in a broader
10 discussion.

11 MEMBER HAMMEL: Hi. This is Joy
12 Hammel. I had a question on how you're assessing
13 social support and relationships. And,
14 specifically, are you doing anything impact on
15 that for dual eligibles and analysis of it?

16 DR. YABROFF: So we have a number of
17 measures in the Medicare Current Beneficiary
18 Survey related to activities of daily living and
19 IADL, instrumental activities of daily living.
20 We also have information about marital status and
21 housing and living structure. So, in some of our
22 survey-based analyses we will have some of those

1 data.

2 CO-CHAIR CHIN HANSEN: Hi. This is
3 Jennie Chin Hansen. And I have my previous
4 background with the original PACE program.

5 As I look at the way of drilling down
6 in terms of factors, which is obviously both
7 appropriate and needed, have you done a corollary
8 look at just the reverse? In other words, having
9 the variables of SES, neighborhood and all, and
10 having outcomes, frankly, that are good? So it's
11 the reverse study to look at kind of cultural
12 deviance of places that are possible so that it's
13 a way of just taking a look at what's different
14 about these communities or areas that allow a
15 reasonable, or if not good, quality to show up.

16 And related to that was a question I
17 was going to ask previously, but offer this: the
18 national PACE programs actually number in 31
19 states now. I think their N is still small for
20 what you're looking at, but it is 40,000
21 enrollees. And wondered if you had a chance to
22 connect with their national association to ask

1 about some of their data. Because I'd say 90, 97
2 percent of their enrollees are duals.

3 DR. YABROFF: So, I'm going to take a
4 first crack. And then I will also ask Karen to
5 talk a little bit about prior work.

6 But, first, in relation to the PACE
7 program, it is something that we've started to
8 look at because we noticed the PACE program
9 includes a frailty adjustment in addition to
10 medical risk adjustment. And so that's an
11 interesting model in thinking about social risk,
12 or at least medical risk that's more common in
13 dually eligible beneficiaries.

14 And then your idea, or your comment
15 about looking not only at those who fare poorly
16 but also at the other side of the scale,
17 beneficiaries and providers that do very well, is
18 well taken. I think that's definitely something
19 we want to be looking at, not to focus only on
20 outcomes that are worse, but also to focus on
21 outcomes that are better.

22 And my understanding -- and, Karen,

1 I'm going to push this back to you a bit -- but
2 there were definitely practices that served large
3 portions of dually eligible populations but had
4 very good outcomes.

5 DR. JOYNT: Yeah, so, in the report
6 there are a bunch of scatter plots. And I think
7 those are fascinating for a couple of reasons.
8 One is that, you know, we distill these
9 relationships down to a single number, right? We
10 say that, you know, hospitals with a high
11 proportion of duals have 15 percent higher
12 readmission rates, or something like that. But
13 in reality, the variability is pretty impressive.

14 And I think your point is very well
15 taken, that understanding that variability is
16 probably pretty important. And I mentioned it, I
17 alluded to it briefly when I said that we saw
18 that the tail of the MA distribution sort of
19 picks back up. And we did some preliminary
20 qualitative work trying to understand what these
21 programs may be doing that could explain the high
22 proportion of duals and the high performance.

1 So, I think there are two
2 possibilities. And one is a happier news story
3 and one is a sadder news story. So, the happier
4 possibility is that there are providers that have
5 figured out how to do really good things for
6 disadvantaged populations, and if we study them
7 we will be able to figure out how we could
8 potentially scale some of those interventions. I
9 think that is almost certainly true.

10 The other piece that may also be true,
11 which would be the sadder news story, is that --
12 and this comes a little bit out of the MedPAC
13 work in MA that harkens back to the previous
14 comment about different types of duals -- the
15 MedPAC published some work demonstrating that
16 having a lot of aged duals, so the over-65 duals
17 group, was not nearly as correlated with
18 performance as having under-65 duals in the MA
19 program.

20 And so it may be that some of the
21 positive deviance we see are actually just us not
22 measuring very well the social complexity of the

1 patients. And I am not a betting person, but if
2 I were I would suspect that both of those things
3 are going on, that there's noise in the data
4 because of how poorly we can measure social risk,
5 and there's real innovation and positive results
6 happening.

7 So, part of what we will hope to do is
8 to suss out both of those things a little bit
9 better.

10 MEMBER ROSS: Hi. This is Clarke Ross
11 with the Consortium for Citizens with
12 Disabilities, which is a Washington, D.C., public
13 policy coalition of 113 national disability
14 groups.

15 And I wanted to suggest complicating
16 your analysis to make it more relevant to the
17 disability community. And these are around the
18 dimensions of social relationships and
19 residential and community context. And I'll
20 suggest four resources for you.

21 So, for 50 years the disability
22 community have been striving to promote community

1 integration and inclusion to fight segregated
2 living situations and to overcome isolation,
3 which is associated with segregated living
4 situations. So, you can look at the Olmstead
5 Supreme Court decision, which operationalized the
6 Americans With Disabilities Act in terms of
7 Medicaid funding and public funding of
8 residential programs, to get citations on this.

9 CMS a year-and-a-half ago published
10 final rules on Medicaid home and community-based
11 service settings rules. These are required
12 dimensions to be called a home- and community-
13 based setting.

14 Three, the National Quality Forum had
15 a committee on home and community-based services
16 and quality measures that has citations of the
17 literature.

18 And, last, in the disability area we
19 have two quality measure programs that are each
20 operated over 20 years: the National Core
21 Indicators and the Personal Outcome Measures.

22 So, to make this relevant to the

1 disability community, community integration,
2 inclusion, dealing with segregation and isolation
3 are essential around the social relationship and
4 residential and community context parts of your
5 analysis.

6 Thank you.

7 DR. YABROFF: Thank you so much.
8 That's really helpful.

9 DR. JOYNT: I was just going to say
10 the same thing. Are any of those measures
11 currently integrated into payment programs? And
12 do you know if like in the home health setting
13 or, you know, any of those settings where there
14 might be some overlap of that? Or is this a
15 separate set of quality measures collected
16 through that group?

17 MEMBER ROSS: So, the National Core
18 Indicators and the Personal Outcome Measures are
19 both used by the publicly-operated state
20 intellectual and developmental disability
21 authorities. And Medicaid is the predominant
22 financing source and state general revenue is

1 matched for Medicaid and state DD systems.

2 These measures are also used for other
3 co-occurring populations. But the arena for the
4 application of the measures are the state
5 developmental disability authorities that use
6 Medicaid.

7 But I'll send to this email address
8 that you've given us summaries and contacts and
9 resource information on all of these things that
10 I've mentioned. And then there are experts in
11 each of these domains that can provide further
12 detail, if you want them.

13 DR. YABROFF: Wonderful. And this is
14 Robin again. I just want to thank you for these
15 resources. And also ask if we might follow up at
16 a later date for additional information?

17 MEMBER ROSS: Sure. I have, again,
18 access to 113 national disability groups, a whole
19 spectrum and variety of groups. And there are 20
20 or so who are quite involved in these particular
21 issues. And happy to refer you to all of them,
22 and each has their own niche or specialty

1 interest and expertise.

2 DR. YABROFF: Great. Thank you so
3 much.

4 MEMBER AGUIAR LYNCH: Hello. Good
5 morning, this is Christine Aguiar Lynch with the
6 Association for Community Affiliated Plans.

7 I was wondering if, as part of your
8 Study B, if you all anticipate recommending to
9 CMS how they could collect some of this data much
10 more broadly? So, taking frailty, for example,
11 that's something that we've been asking CMS to
12 consider adding that to their Medicare risk
13 adjustment payment. But a limitation with that
14 is that they don't collect that information
15 widely. And as you guys recognize, MCBS and the
16 ACS are really small sample sizes.

17 And then if it's not possible to
18 collect the social risk factors data broadly for
19 all Medicare beneficiaries, do you anticipate
20 recommending a proxy measure that CMS could use
21 instead?

22 DR. YABROFF: That is an excellent

1 question. One of the things we're planning on
2 doing is evaluating claims-based measures, which
3 would, of course, be available on all fee-for-
4 service beneficiaries, of things like frailty,
5 that might be possible to use.

6 As part of the National Academy's
7 reports, the committee had a list of different
8 types of data, and also their current
9 availability and where additional research might
10 be needed. They also identified different
11 criteria for thinking about data and how making
12 data better available and when. You know, some
13 measures are fixed or fairly fixed, and that
14 might be collected at entry into the Medicare
15 program, whereas other measures might change over
16 time. And so really the big concern is the
17 burden of data collection to beneficiaries and
18 providers.

19 So I think it's definitely a balancing
20 act in terms of having sufficient information to
21 better understand health disparities in outcomes
22 and performance. But also, you know, having

1 those data, additional data would be wonderful.
2 But there is a burden, of course, in collecting
3 those data.

4 And I don't know, Karen, did you want
5 to add anything to that?

6 DR. JOYNT: You know, I think in the
7 long term, if we put our, like, futuristic caps
8 on for a moment, one could imagine a lot of these
9 data could come from electronic health records
10 and from other data sources that would not be as
11 burdensome to report.

12 Obviously, patient-reported outcomes
13 would be the other end of the spectrum where
14 they're highly burdensome to both report and
15 collect, but extremely important. And so finding
16 a balance of ways that we can enhance data
17 collection, harmonize across different programs
18 and measures and private/public, and, you know,
19 from a big picture standpoint there's a lot I
20 think we could do. By "we," I mean a group much,
21 much bigger than those of us on the phone. But
22 to try to get at some of those things. And at

1 the same time, we will need the nitty-gritty,
2 patient-reported stuff to also be growing.

3 So, we are not in a position to make
4 specific recommendations around that right now.
5 But you've sort of zeroed in on one of the key
6 things that would have to happen in order for a
7 lot of these things to move forward.

8 DR. ZUCKERMAN: And this is Rachael
9 Zuckerman from ASPE. I just want to add one more
10 thing sort of in terms of what we're tasked to do
11 and how we're tasked to do it in the law itself.

12 So we are asked to make
13 recommendations. And they don't necessarily need
14 to be in the report. So we're, as Robin said,
15 we're going to start looking at these things as
16 we do the second report. But it's possible that
17 we will sort of continue thinking about it and
18 the recommendations will come after the second
19 report.

20 So, don't get disappointed if it's not
21 right there right away.

22 MEMBER CUELLAR: I'm interested to

1 hear what you think the state of research is on
2 measuring income, both at the individual level
3 and at the area level? It looks like some,
4 you're deferring some work to your Study B, and
5 what might that work look like?

6 It looks like you may have looked at
7 the ZIP Code median income. Have you thought
8 about using, leveraging some of the work of Raj
9 Chetty and looking at the disparities in income
10 in the community as opposed to just a measure of
11 the central tendency?

12 So those are two different questions.
13 What do you have in the hopper in terms of
14 looking at income and data sources for that? And
15 then thinking about income, area income measures.

16 DR. YABROFF: Those are both great
17 questions and a little bit complicated,
18 especially for the Medicare beneficiary
19 population. We are looking, with MCBS we are
20 looking at data on assets, which may be more
21 informative when thinking about socioeconomic
22 position than actual income. Although we will

1 have some data on income as well.

2 And we do plan on looking at area
3 level median income, things like that. But also
4 we are exploring other neighborhood sort of
5 deprivation measures which would encompass things
6 like disparity in income within an area.

7 So, I think it's --- we are in
8 process, I think, on all of those factors. But,
9 you know, income can be complicated to measure,
10 in part because many people are uncomfortable
11 reporting it.

12 MEMBER CUELLAR: So if you don't mind
13 my following up, if you're doing the analyses
14 using surveys like MCBS, that would imply that to
15 implement it we'd have to have a data source like
16 a survey, as opposed to relying on something like
17 a census?

18 DR. YABROFF: Yeah. One of the
19 advantages of linking claims data to the American
20 Community Survey at the individual level is that
21 we can actually explore that in more detail. And
22 it may be that for some measures like income,

1 collecting it at the area level is sufficient.

2 But there may be other measures, like
3 comparing individual income to income disparities
4 in an area, that are really quite different. So,
5 I think it's going to be one of those it depends
6 on what the measure is and what we find.

7 MEMBER CUELLAR: Thank you.

8 DR. YABROFF: Thank you.

9 MEMBER LUTZOW: Yeah, this is Tom
10 Lutzow again.

11 Certainly, you know, you do want to
12 look at claims data and so on. But there's, the
13 real story about social risks is missing from
14 that data.

15 There are ZIP Codes in downtown
16 Chicago where Medicare-funded skilled nursing
17 visits to the home don't occur without an armed
18 guard present to the nurse. And I'm not sure
19 where armed guards show up in the claims stream.
20 And a study where you were to take those ZIP
21 Codes and look at Medicare-funded home visits in
22 those ZIP Codes and compare them to a suburban

1 Washington location and ask the question how many
2 of those suburban Washington skilled home visits
3 were accompanied by an armed guard, you would
4 begin to appreciate or be able to tell the story
5 about how social risk really does affect the
6 delivery of healthcare.

7 If you look at PCP follow-up visits,
8 post-inpatient stays in those Chicago ZIP Codes
9 you would find, I think, that they are noticeably
10 depressed because those folks are so fearful they
11 lock themselves in their homes. They don't get
12 out for fear of their lives. And that, again,
13 affects their interaction with the healthcare
14 system.

15 So, that kind of information doesn't
16 show up in the claims stream. And it doesn't --
17 therefore, the claims stream really can't tell
18 the story. And you have to get out, I think,
19 and, you know, ask those kinds of deeper
20 questions.

21 DR. YABROFF: Yeah. And I agree with
22 you that those data are not readily available in

1 claims. This is also an area of exploration
2 where we can look at residential and community
3 context factors related to things like crime and
4 things like there are a number of, increasingly a
5 number of measures of things like social cohesion
6 that occur at the community level. And so that
7 is definitely something we are exploring using
8 data from sources, other sources that have
9 information that are important for social risk.

10 But I, I think it's a really important
11 point that without understanding the context of
12 where people live, it's difficult to understand
13 what's happening in terms of their outcome.

14 MEMBER BRINGEWATT: Yes. This is Rich
15 Bringewatt again from the SNP Alliance.

16 Two things. One is, each year the SNP
17 Alliance does an annual survey of its members
18 that includes both quantitative data and
19 qualitative data. And we're, we just pulled
20 together the report from the end of last year.
21 And part of the qualitative report focused on
22 questions about social risk factors.

1 One of the questions included among
2 the members, and they all have high
3 concentrations of plans serving duals. But the
4 top social risk factors observed by their care
5 managers, and in order of priority, frequency, it
6 was, number one was low health literacy,
7 difficulty understanding health information.

8 Two was low income, poverty status.

9 Three was lack of mental health-
10 related supports.

11 Four was living alone, few social
12 supports.

13 Fifth was a tie between housing
14 instability and transportation barriers.

15 Now, that's qualitative information.
16 But I think it's probably useful information as
17 it relates to care managers who serve these
18 populations in terms of what they see as the
19 primary risk factors. And we'd be happy to share
20 more about that survey and some of those
21 findings. And would appreciate your input in
22 terms of what we might do next with some of that.

1 The second thing I wanted to note is
2 simply, is a question as it relates to teasing
3 out relationships particularly, I think, between
4 social risk factors and care complexity. And it,
5 you know, it seems to me like a very old study,
6 Linda Fried in I'm going to say maybe 2004 or 5,
7 but there was an untangling of chronic conditions
8 looking at measurements for frailty, comorbidity,
9 and different types of disability.

10 And it seems to me like that construct
11 might be a useful place to look in doing some
12 looking at the relationship between social risk
13 factors and those, those particular factors in
14 order to know. You know, it may be that some of
15 these things are influencing other things in the
16 mix. And just a thought about what might be
17 observed there.

18 DR. YABROFF: Thank you. As to the
19 first comment, I think we would definitely be
20 interested in seeing the results of your survey.
21 And so I'm going to ask you to use the email
22 address, that way we all, all will have a chance

1 to look it.

2 And then in terms of teasing out
3 different relationships, we're definitely
4 familiar with Linda Fried's work. And we'll
5 circle back on this particular study you're
6 suggesting.

7 I also want to make the point that
8 increasingly data are available on things like
9 housing insecurity and food insecurity, not
10 always at the individual level, but those sorts
11 of measures we can really start to think about a
12 neighborhood and social context, in new and
13 different ways. So we are definitely going to
14 draw on expertise from our colleagues who have
15 done work in that area.

16 MEMBER PARKER: Hi. This is Pam
17 Parker.

18 Maybe I missed this because I had to
19 step out. But in terms of the data sources that
20 you looked at or you're thinking of looking at,
21 have you looked at -- I think the biggest source
22 of detailed functional status and, you know, home

1 living and all of that is state Medicaid data on
2 home community-based service clients. And
3 there's just, you know, a huge amount of data
4 that's collected in the assessments for that
5 group.

6 So anybody that's dual and frail or
7 disabled and meets the criteria for, you know,
8 home community-based type services, states have
9 huge repositories of data in incredible detail on
10 that. And not all the states perhaps have that
11 data automated, but I think a lot of them do.
12 Some like, for instance, where I'm from in
13 Minnesota they use it for risk adjustment.

14 So there, that's probably the richest
15 data source I can think of for some of the things
16 that you're talking about.

17 DR. YABROFF: Yes. Thank you for that
18 suggestion.

19 I will say that the process of linking
20 Medicare claims data with Medicaid data can be
21 complicated. But I do agree that it's
22 potentially a very rich data source.

1 MEMBER PARKER: Yeah, Minnesota does
2 have -- has had linked data. But I agree with
3 you that it's underestimated how complex that is.
4 I've seen people think they can do it and it
5 hasn't ---

6 And the other obvious thing is, of
7 course, you know when you're talking about all
8 these other sources of data for income and asset
9 status on dual eligibility, that's the one thing
10 that is a good proxy, to use the dual status
11 indicator because that's what it's about, is
12 income level first of all. And so, you don't
13 really have to go that much further when you're
14 talking about the duals I don't think.

15 CO-CHAIR MONSON: So this is Michael
16 Monson. I'm with Centene.

17 Just I want to build on Pam's point.
18 I would agree that the data that sits in those
19 comprehensive assessments is very robust. And
20 one way -- Stacey, don't look at me askance when
21 I say this -- but one way that you might want to
22 think about getting at that is that the MMPs have

1 all linked that data. Right? So, and I would
2 say all the FIDE SNPs have also done that.

3 So, that would be a place to
4 potentially look to for information because
5 there's been a ton of work by states, plans, and
6 MMCO to make sure that that -- at enrollment that
7 we know who's who. And it is not easy. But that
8 is all linked. So that is a place, that is a
9 potential starting point in order to find some of
10 that information.

11 The other piece that I wanted to just
12 advocate for was to think about the setting of
13 where the person lives. And that might, in fact,
14 have an implication for how you think about
15 social risk. And we've got this population, dual
16 eligibles, there's a disproportion of dual
17 eligibles who live in institutions. I think we
18 can't ignore that when you look at that as a risk
19 factor because institutions have all sorts of
20 problems.

21 And I know you'll say, you'll have
22 trouble figuring it out, but again that data is

1 actually available in the Medicaid data because
2 the rate cells are all linked to institution
3 versus home- and community-based services.

4 And then the final thing I would just
5 say on that point is that you probably want to
6 think about crossing the -- people who are on the
7 waiver versus people who are not. Because if
8 you're accessing waiver services, I think we
9 would all likely think that people who have
10 waiver services probably have a better health
11 outcome, or hopefully have a better health
12 outcome than those who do not have waiver
13 services.

14 And, I mean that could be, that could
15 explain your -- that tick on the MA plans at the
16 backside. Those could all be FIDE SNPs that are
17 actually accessing waiver services. So I will
18 leave it at that.

19 Did anybody else have any other
20 comments or questions?

21 MEMBER PARKER: Could I just add to
22 that waiver or personal care.

1 CO-CHAIR MONSON: Yes.

2 MEMBER PARKER: It might be a state
3 plan option.

4 CO-CHAIR MONSON: Yes, state plan.
5 Yes.

6 MEMBER PARKER: So not just the waiver
7 but also the personal plan.

8 CO-CHAIR MONSON: Good point.

9 DR. JOYNT: Yeah, and to make it even
10 broader, you know, we've thought a lot about what
11 -- you know, we are essentially tasked with and
12 looking at Medicare. But all these folks operate
13 within a context of their state-based services,
14 their community-based services, the communities
15 they're in. And, you know, not just from a
16 health standpoint but from really a community,
17 social support, and social organization
18 standpoint. And that sort of stuff is almost
19 certainly influencing people's outcomes.

20 And it's really tricky to think about
21 how we might access and really understand some of
22 that context. That's a great point.

1 CO-CHAIR MONSON: Joe.

2 MEMBER BAKER: This is Joe Baker from
3 the Medicare Rights Center.

4 So, we've spent a lot of time talking
5 about beneficiaries. So I guess a broad question
6 is, you know, we haven't really talked about the
7 quality of the providers. So, what are you doing
8 to take a look at the actual provider community
9 that folks are accessing, and who they are, and,
10 you know, whether it really is resources, whether
11 it is something else? And how are you, you know,
12 looking to approach that, even drilling down to,
13 you know, individual providers if that's possible
14 or if that's something that you feel is, you
15 know, you want to do?

16 DR. JOYNT: We have not thus far
17 drilled down to individual providers. In some of
18 the work that the National Academies did they did
19 some best practices work in which they did look
20 at examples of organizations that had been doing
21 good work in this area. And I certainly think
22 that's important.

1 We have, particularly for physician
2 groups and things where sample sizes get pretty
3 small, it's actually, it's kind of tough to sort
4 out performance issues. So we've not really
5 drilled down onto the individuals yet.

6 We may do some follow-up work
7 qualitatively trying to understand what high
8 performance looks like in different contexts.
9 But I think we have a lot to learn about context
10 before we feel confident that individuals -- that
11 we can really assess some of those details in the
12 context of social risk.

13 MEMBER BAKER: Great. Maybe I
14 shouldn't have said individual providers because
15 then we get all crazy about, like, oh my gosh,
16 Dr. Smith is going to get slammed.

17 But I'm even thinking about systems
18 or, you know, look, we all know there's a crappy
19 hospital in every town. So, you know, I mean, --
20 and physicians there either don't have resources
21 or, you know, they're not the best physicians or
22 group of clinicians in that particular community.

1 And yet, that community is kind of relegated to
2 that particular institution because of the fact
3 that it's, you know, because of travel and other
4 restrictions.

5 So, I guess the broader question is
6 what are you doing to focus on, you know, because
7 one of the lists of the things that was in your,
8 you know, the two pieces or the provider piece
9 was the quality of the provider, so what are you
10 looking at in particular with regard to that to
11 come up with either recommendations or
12 indications of that, something that -- and the
13 solution could be we just need better quality
14 providers, right? Or we need different levels of
15 providers and a different mix of providers for
16 certain communities. So what might be the data
17 that you're looking at to kind of get at the
18 bottom of that?

19 DR. JOYNT: I'll give you an attempted
20 response, but take with all attendant caveats,
21 which is I think there's a lot of enthusiasm on
22 the policymaker side that things like value-based

1 payment programs, accountability, and measurement
2 will improve quality even for the poorest
3 performers. And I think there's some initial
4 indications from the Readmissions Reduction
5 Program that some programs have
6 disproportionately led to improvement among the
7 worst performers.

8 I think there's pretty strong feeling
9 in the clinical community that there are
10 providers for whom simply putting financial
11 incentives in place is not going to adequately
12 change anything because the problems go much,
13 much deeper than a lack of financial incentive.
14 And I think that's sort of the groups that you're
15 talking about.

16 And I will just say we don't know how
17 to solve that problem and have not, and will not,
18 I think, pretend to know the answer to that one.

19 CO-CHAIR MONSON: Well, Karen, Robin
20 and Rachael, thank you so much for taking the
21 time this morning. This has been, I think this
22 committee has found this to be extraordinarily

1 helpful. And thank you for just doing this work.
2 This is very important work. And it's not easy.
3 But you are, you guys are pushing the ball in a
4 very serious way forward on a very important
5 topic.

6 So thank you for your service.

7 DR. JOYNT: Thank you for having us.
8 And please, everyone, do feel free to reach out.
9 We heard -- I have a bunch of scribbled notes
10 with all the great stuff that we heard. But
11 it'll be much, much more accurate if you all
12 reach out if there's stuff that you want us to
13 know, reports you want to send, please be in
14 touch.

15 DR. YABROFF: Right. Right. And I
16 will reiterate that I have also been taking
17 scribbled notes. But I can't always read my
18 writing. So thank you very much. We really
19 appreciate the opportunity to speak to you today.

20 DR. ROILAND: And we can send you a
21 transcript as well. That way you'll have your
22 notes.

1 DR. YABROFF: Oh, that would be
2 wonderful. Thank you.

3 DR. JOYNT: And we'll sign off. Thank
4 you very much.

5 DR. ROILAND: You're welcome.

6 MS. MUKHERJEE: Hi, everybody. So
7 this is Debjani again. What I'm going to do now
8 is continue the discussion of risk adjustment and
9 sociodemographic factors and just go over the
10 homework that we had sent around.

11 And basically, the homework was asking
12 all of you to think about five social risk
13 factors most relevant for the duals population
14 that HHS and CMS should keep in mind while sort
15 of conducting and evolving their work, and for
16 each of those social risk factors identified we
17 wanted sort of some practical information of is
18 that data available anywhere, is it available?

19 So, with that I'm going to take you
20 through the first graph.

21 So, basically what we did was we
22 provided one of the graphics from the ASPE report

1 which listed all the social risk factors and
2 which ones were easy to collect and not collect
3 and things like that. And asked for you to sort
4 of give us some feedback and add to that list.

5 And so the number one category was
6 social support, loneliness, widowhood, and social
7 capital.

8 Number two was sort of two groups,
9 residential and community context, socioeconomic
10 position, status, and income.

11 And some of these, because we didn't
12 ask for a definition, some of these based on how
13 you're defining could sort of overlap. But I
14 just wanted to sort of let you all know that,
15 that we realize that some of -- these are not
16 completely sort of independent of each other.

17 The third group was race, ethnicity,
18 language, gender, sexual orientation.

19 The fourth group was education,
20 accessible safe housing.

21 The fifth was a large group, rural
22 isolation, segregation, locus of control,

1 valued/devalued status.

2 And finally, the last group, the sixth
3 group was food insecurity and medical risk
4 factors.

5 And what these groups did was they
6 kind of built on the ASPE factors, risk factors.
7 And the ASPE risk factors were income, education,
8 dual eligibility, wealth, race and ethnicity,
9 language, acculturation, gender identity, sexual
10 orientation, partnership status, living alone,
11 social support, neighborhood, geography, housing,
12 and other environmental measures.

13 So they, even though it wasn't a one-
14 to-one match, we kind of captured all the ASPE
15 categories.

16 And then I think this was sort of
17 something we really were looking forward to, sort
18 of the part two, which is current and potential
19 future data sources that could be and should be
20 used to capture these factors.

21 Dual eligibility benefit level, full
22 benefit was a proxy for income. Area deprivation

1 indices were another one for neighborhood sort of
2 geographic data.

3 Medicare Advantage plans for primary
4 language; Medicaid agencies for sort of race,
5 marital status; county infrastructure for
6 community context, geographical data, census
7 tract, health record.

8 And some other ones were the
9 University of Minnesota and University of
10 California project that we're going to hear from
11 later today, community context, isolation,
12 poverty, medical risk factors.

13 The National Core Indicators -- so
14 that should make Clarke very happy that it was
15 sort of one of the things that came up. And that
16 would not only talk about communication status,
17 social capital, isolation, also giving some data
18 on disability, LTSS/Medicare-Medicaid Plans for
19 housing, social support, food insecurity, food
20 security, access to transportation, the CAHPS,
21 HCBS.

22 So, we got a good sort of

1 representation of where the data could be found.
2 So we want to sort of provide that to CMS so that
3 there's -- we're not only providing our thoughts
4 on the important social risk factors but also
5 where they could be found so that there's some
6 practical guidance as well.

7 And with that, I will turn it over to
8 the group for guidance, from measure developers
9 specifically, practical guidance on how can they
10 use these based on sort of the homework
11 information and sort of looking at gaps that we
12 have, and sort of input to CMS on how can all
13 these social risk factors and sociodemographic
14 factors be used and garnered to sort of fill
15 those gaps.

16 And we might have talked a lot about
17 this and sort of killed the topic, but I just
18 want to get some more thoughts.

19 MEMBER ZLOTNIK: I've been thinking a
20 lot about this when I was doing the homework,
21 and then kind of really reiterating, thinking
22 about it with the presentation earlier this

1 morning. At some level this information is kind
2 of like, you know, it's not about medical care.

3 And these issues are so complex and
4 sort of confounded together. And so when I think
5 about, you know, what would be helpful in terms
6 of measure development I think of either sort of
7 in urban or sort of very rural communities have
8 many of the same issues. And people are working
9 in, you know, low staff, high case load, high
10 work load, complex needs.

11 So one piece is like how could you
12 develop a measure that measures something that's
13 really complex but measures it in an easy way so
14 that people would actually use the measure?

15 I don't have the answer to that
16 question. But that's kind of a little of what,
17 you know, has been kind of going through my mind.

18 The other piece is, once again I don't
19 have a suggestion as a measure developer,
20 developed, but are really particularly sort of
21 transgender populations and people who really
22 are, you know, kind of isolated, are not well-

1 served by the healthcare community at all. We
2 have a doctoral fellow who is actually doing a
3 dissertation on that this year in terms of really
4 looking at, you know, do medical providers, will
5 they serve trans folks or not.

6 So, those are really, I guess I want
7 to add to the questions and dilemmas. I don't
8 have any great suggestions at the moment in terms
9 of measure development. But we have to sort of
10 balance ways to tease out complex and
11 intersecting information with, also, measures
12 that are easy to use.

13 MEMBER CUELLAR: I agree with Joan,
14 the National Academy report has this nice
15 framework for -- not prioritizing but
16 categorizing these indicators by whether there
17 are data and how hard it would be to get the
18 data. And I think that's an important
19 consideration. There are lots of things here
20 that we would love to see that would be very
21 expensive to collect, even if we had the right
22 measure.

1 MEMBER LUTZOW: Yes, I mean just
2 picking social capital, that certainly -- I mean
3 isolation is not helpful and creates greater
4 risk.

5 Where -- I mean certainly you've got
6 buddy programs within the IDD group where these
7 programs that intend and actually do align
8 someone with a disability typically with some
9 other person who's in high school. And they have
10 a buddy relationship and with the purpose of
11 developing social capital.

12 You know, I think if in the assessment
13 process it's identified as a problem for an
14 individual, you know, there could be easily a
15 measure developed as to whether that goal or that
16 need was addressed in the plan of care. And a
17 listing of possible solutions, some kind of
18 affiliation with a relative, affiliation with a
19 friend, affiliation with a volunteer, a social
20 engagement in some way could all be solutions to
21 that, to that need.

22 I'm not sure why it wouldn't be an

1 acceptable measure if it's identified in the risk
2 assessment as a need that has risk attached to
3 it.

4 So, we try to do it. And when we see
5 it as a need, certainly it has value in the area
6 of medication adherence, reminders for, you know,
7 to keep an appointment with a primary care
8 resource. It has transportation value. This
9 kind of, you know, building social capital around
10 somebody who's isolated, it has value.

11 And it's -- now is it outside of the
12 medical treatment area? Yes, it is. But it has
13 an impact on the success of a medical plan.

14 So, are we afraid to do this? Is it
15 a question that it would be gamed? Maybe. You
16 know, here's where I think we have to say that
17 this population has got some unique needs that
18 strictly medical measures can't get at.

19 MEMBER BRINGEWATT: The SNP Alliance
20 has a position paper on this topic in terms of
21 guidelines for measure developers for dealing
22 with social determinants of health. I had every

1 intention to bring copies of that here today, and
2 forgot them. So, I don't have them here today.

3 But I do want to highlight what the
4 recommendations are that's contained in that
5 report that was put together through our
6 performance evaluation leadership group and other
7 consultants that have been dealing with social
8 determinants of health.

9 The overall recommendation is that CMS
10 has a minimum set of standards for measure
11 developers and stewards to consistently test the
12 measures that what, you know, if everybody kind
13 of chooses their own approach some may be really
14 good and others may not, and it might be that
15 some measures really aren't adequately tested
16 when they're found, that there isn't an effect of
17 social risk factors. And it may be because of
18 the methodology used.

19 So in terms of suggested requirements,
20 there's a half a dozen different categories that
21 we had recommendations on. One relates to the
22 sampling, the importance of including a minimum

1 percentage of younger adults with disabled --
2 with disabilities, as well as older adults with
3 multiple conditions, that if you have, you know,
4 the sampling mix of subgroups needs to
5 appropriately represent the broader problem in
6 relation to the unit of analysis.

7 Use the smallest geographical area as
8 unit of analysis. Studies show that variances
9 are masked when a 5-digit ZIP Code data source is
10 used. They really need to dig down to a 9-digit
11 data ZIP Code as the focus. And, you know,
12 there's also some neighborhood data level that is
13 shown to be highly predictive of individual
14 health outcomes.

15 Variables tested, you know, it seems
16 like it would be important to establish a minimum
17 set of factors. As the starting point, we
18 suggest that it would include dual status,
19 disability status, factors with significant
20 effect on outcomes such as living in a poor
21 neighborhood, single person household size,
22 limited social supports, low education level, and

1 limited education proficiency. Those are factors
2 that are known to have a relationship, so it
3 ought to be tested. Whatever testing is done
4 should include those.

5 So just that accommodations and sound
6 methods of administration are addressed to ensure
7 that the methodology accommodates whatever they
8 use, their survey methods accommodates low
9 income, diverse, non-English speaking
10 beneficiaries, shouldn't require beneficiaries to
11 use cell phones, computers or internet. There's
12 some other things like that, recommendations.

13 Two more. Transparency: if there is
14 measure development work, if there's analysis
15 work done it should be public so that other
16 measure developers can look at it and make some
17 suggestions and make observations as to whether
18 they think that it has been adequately tested.
19 And then dissemination in terms of, you know,
20 wider public distribution of the kind of analysis
21 that was done.

22 We're not saying this is the only way

1 it should be done. Our intent here is to really
2 create a kind of a talking point paper and
3 perhaps stimulate other thoughts that might
4 generate other recommendations. But we think
5 that without some sort of minimum standards and
6 guidance that we're really not going to get the
7 kind of evaluation that everybody is looking for.

8 MEMBER HAMMEL: Just an addition to
9 your instruments, too, in addition to the NCI and
10 some of the ones coming out of the disability
11 world. I've been looking at the PROMIS
12 initiatives through NIH, right, the patient-
13 reported outcomes. Because there's been so much
14 more validation of those with people with
15 disabilities, people under 65, specific different
16 groups there that they've been doing both
17 qualitative and quantitative validation.

18 And they have a whole set of lovely
19 social supports. They're really spent a lot of
20 time on instrumental support, emotional support,
21 intimate, you know, support. Different scales
22 for each of those but also short forms of all of

1 them. So you can do only, like, a 3-item version
2 that's as reliable and as valid as the longer
3 version.

4 They also have a new one out on
5 societal stigma and the culture of your community
6 and neighborhood on how you would rate it as a
7 person with a disability or a person with any
8 kind of diversity, kind of things in it.

9 So, just to note, they spent like --
10 it's a group of rigorous researchers, so even as
11 I was looking at some of the stuff earlier
12 yesterday, some of those surveys felt really kind
13 of uninformed to me, like, from a rigor
14 standpoint. You know, like not even having the
15 right scale, right, you know, to even look at
16 things. Whereas PROMIS, you know, started as a
17 research initiative.

18 And now it's available as a computer-
19 adapted testing. Easy available, anybody can
20 join it. It's free. And it has done some really
21 nice validation of the social and system level
22 kinds of things that are affecting people in a

1 patient-reported outcome measure.

2 MEMBER CUELLAR: Is there some
3 communication going on to have maybe someone
4 shepherd a measure through the NQF process?

5 MS. MUNTHALI: Actually, there is. We
6 have been talking with the PROMIS folks through
7 our Measures Applications Partnership. And that
8 group took an early look at the survey and gave
9 some feedback on potential measures that can come
10 out of the survey. So we're hoping that those
11 come through our endorsement process at some
12 point.

13 MEMBER CUELLAR: Any idea what that
14 timeline might look like?

15 MS. MUNTHALI: I don't know the
16 timeline. I would say maybe in the next couple
17 of years.

18 MEMBER CUELLAR: Okay.

19 MEMBER POTTER: I would love for that
20 to come about, but there still has to be a data
21 infrastructure. So somebody has to collect the
22 measure. So that means it's either collected at

1 the clinician's office or it's collected by the
2 health plan. And I think that's a limitation of
3 some of these things.

4 And I'm back to the point that Joan
5 made about how to operationalize any of this in
6 terms of infrastructure. So, I'm always coming
7 back to data that are collected across the board,
8 i.e., the census data and all of the things that
9 hang off of the census data, as just one
10 approach.

11 One thing that's happening in the
12 survey research world is there's always been an
13 issue around how do you adjust for non-response.
14 And so there's follow-up surveys that
15 interviewers fill out when they attempt to
16 collect survey data about the neighborhood that
17 the person was in, and things like that. And
18 those kinds of information for a while now have
19 been used to help adjust for non-response. It's
20 called paradata. It's not always available
21 publicly on the survey.

22 But beyond that, now people are using

1 things like Google Earth to look at neighborhoods
2 and to attach measures to it. So if there was a
3 database that used something like Google Earth
4 and it was at the 9 level ZIP Code level, and it
5 was a national database, then that's something
6 that could be used by measure developers and
7 others in operationalizing.

8 CO-CHAIR MONSON: I'm just going to
9 pause for just a moment because Jennie,
10 unfortunately, has to leave. But I wanted to
11 make sure we took an opportunity, because Jennie
12 has been shepherding this committee for several
13 years now, and thank her for her work as co-
14 chair. Because I don't think we would have
15 gotten to where we've gotten today and all the
16 great work without her.

17 (Applause.)

18 CO-CHAIR CHIN HANSEN: Thank you.
19 That's way too generous. As many of you know,
20 it's, frankly, a lot of the substantive
21 contribution and the fact that this is so
22 outwardly focused back to the consumers. So, you

1 know, let's hope that this is a pause. And I
2 thank you all for your contributions and your
3 teamwork and review in this process.

4 As you can tell, I'm coughing way too
5 much and causing enough of a disruption that I'm
6 just going to head home and take an earlier
7 flight. And so I want to say thank you to all
8 the NQF staff. Some of you've been here a long
9 time, some of you more recent, but, you know,
10 talk about quality, the quality of the folks here
11 all around are fabulous.

12 So, thank you very much. And needless
13 to say, I think we're all going to dog this
14 topic. So, we'll still be adding things. So,
15 thank you for everyone's heartfelt and
16 substantive contributions.

17 And, Stacey, I know this is your first
18 meeting. You've been really able to manage, you
19 know, this duality that you play. And you know
20 now that there's a lot of people here supporting
21 the work that you're trying to do at CMS.

22 So thank you very, very much,

1 everybody. I will leave you in peace. And also
2 mitigate some further exposure here.

3 CO-CHAIR MONSON: Feel better, Jennie.

4 MS. MUKHERJEE: And, Jennie,
5 definitely thank you for the staff. You've been
6 sort of a great support, especially through the
7 transitions and your knowledge and sharing that
8 and being there to support us when we need you
9 even if it's in a pinch, so.

10 CO-CHAIR CHIN HANSEN: Thank you.

11 And I don't know if Alice Lind is on
12 the line. For those of us who've been here for a
13 long time, Alice, your leadership has really
14 helped us move as far as we have. So, thank you
15 very much for your leadership in this work.

16 MEMBER LIND: Thank you, Jennie.

17 (Applause.)

18 CO-CHAIR MONSON: So, sorry to
19 interrupt the flow.

20 So, we were having this conversation
21 kind of around the instruments. So why don't we
22 just continue -- does anyone want to continue

1 that? I know, Clarke, you had your tent up. Is
2 it on this topic? Okay, go for it.

3 MEMBER ROSS: So, a research question.
4 We have these existing and functioning quality
5 measurement systems with narrow purpose. And how
6 do we get the resources and target the resources
7 to expand those systems to other populations in
8 other settings?

9 So, the National Quality Forum has had
10 several presentations I've been at on PROMIS.
11 And I took PROMIS to the National Health Council.
12 The National Health Council is a multi-sector
13 coalition that's been around since 1920. And
14 there are 52 voluntary health agencies: heart,
15 cancer, lung, MS, the big ones. And they were
16 very skeptical of the existing PROMIS because
17 they said, well, PROMIS is in the hospital, the
18 clinical setting, has predominantly been used
19 with orthopedic and cardiology. And what do they
20 know about X, Y, and Z?

21 And that's our typical human response
22 to most ideas to use something is where it's

1 currently used, and, well, look at all the
2 inadequacies. Because of the National Quality
3 Forum, this work group and the Patient Reported
4 Outcome Committee, so broken record on the
5 National Core Indicators. The National Core
6 Indicators were designed for people with
7 intellectual and developmental disabilities and
8 slowly has gotten into people with co-occurring
9 IDD and mental illness, because that's the
10 prevalence of the population.

11 Because of the recommendations of two
12 National Quality Forum workgroups, the
13 Administration on Community Living developed an
14 investment into the National Core Indicators with
15 state aging and disability agencies to see -- to
16 pilot, to adapt and then pilot how it would work
17 with physically disabled, non-elderly folks, and
18 aging folks.

19 So, these are the -- rather than
20 recreate the wheel and just criticize existing
21 approaches, National Core Indicators and Personal
22 Outcome Measures each have been functioning for

1 over 20 years in multiple states. So, how do we
2 convince the measure developers to get out of
3 their comfort zone but invest money in, and let
4 people have some running room in order to
5 develop, expand and adapt, because you have to
6 adapt for different populations and settings.

7 And how do we -- and is that a major
8 recommendation? Some of the National Quality
9 Forum reports have said we need to invest more in
10 measure development. And so I'd like to carry
11 that theme and here PROMIS is an example, and
12 National Core Indicators and Personal Outcome
13 Measures are examples, that have done a little
14 bit but need to do a lot more.

15 Thank you.

16 MEMBER PARKER: As I've been sitting
17 here listening to this, we're in some ways
18 rightfully, but overlooking one of the major data
19 sources that CMS uses now in both the PACE
20 frailty adjustment and FIDE SNP, and for other
21 purposes. And Stars is the HOS, Health Outcome
22 Survey.

1 And now I can't in some ways believe
2 that I'm bringing this up as a source of data
3 because we've got so many problems with it. But,
4 for instance, it's not well available in
5 language, in terms of language and ethnicity
6 groups. It doesn't have a good proxy
7 methodology. It says nothing about proxy. It's
8 a year -- you've got to be in it two years. And
9 half the elderly are dead, you know, in the
10 second year.

11 So it doesn't, it isn't appropriate
12 for people with cognitive impairments. It's a
13 terribly, terribly small sample. And it's not
14 done at the planned benefit package level, it's
15 done at the broader health plan level, so it's
16 all mixed up, you know. So if you're trying to
17 get at dual measures and solve some of the
18 problems that you're talking about in the ASPE
19 report, it's a problem.

20 However, it's done all the time. It's
21 something that CMS, you know, administers and is
22 invested in it. And it needs to be fixed. At

1 the same time it has a lot of the data elements
2 that we're talking about in it. It has -- you
3 know, there's income, sex, age, functional status
4 stuff, widowhood, single, education level, some
5 of the other, you know, it could have the 9-code
6 ZIP Code maybe, you know. It is -- you know, so
7 if you increase the sample size, fix these other
8 problems that should be fixed anyway.

9 One of the things that we did in
10 Minnesota was gathered all -- there's a little
11 profile that goes along, each health plan gets a
12 profile, each Medicare plan gets a little
13 profile. We took the profiles of the plans that
14 had big Medicare broad plans versus the ones that
15 just served duals, and so we had a bunch of D-
16 SNPs. And we compared the two profiles. So we
17 compiled them and compared them, you know.

18 And, you know, it was startling, the
19 differences. I mean, you could see the
20 difference in the income level and the education
21 level and the, you know, where the -- the
22 widowhood and the, you know. So all kinds of

1 proxies in there for some of these things we've
2 been talking about you could --- that was very
3 startling.

4 So somehow if that instrument were
5 fixed and utilized in a better way -- I'm just
6 saying, you know, it should be anyway -- it could
7 be a source of data that's collected at a, you
8 know, a larger level. And it is already relied
9 on. And it wouldn't be wasted effort like it is
10 right now because it's such a poor instrument.

11 MEMBER LAKIN: I sort of feel like my
12 job here is to support Clarke in everything he
13 says. But, you know, I have been struck with a
14 lot of this discussion and this discussion of
15 neighborhood factors sort of brought it back to
16 me.

17 You know, we're so often looking for
18 the easy variables that are already there that we
19 can draw on and pump them in and see whether we
20 can explain some of the variance in what we pay
21 or what we achieve.

22 And, you know, I'm struck. I've done

1 a lot of work with the NCI, merging data from
2 many different states into a large data set so we
3 can begin to look at a lot of individual factors
4 that are predictive of outcomes for people. And,
5 you know, in this whole area of neighborhood I've
6 just been struck with how persistent a single set
7 of variables is to the outcomes that people
8 experience, whether they're loneliness, whether
9 they're inclusion, kind of whatever they are.
10 And that is whether people say they're afraid in
11 their home and they're afraid in their
12 neighborhood.

13 And, you know, it seems to me that,
14 you know, we run around grabbing census tract
15 data and 7-digit or 9-digit ZIP Code data trying
16 to get a proxy for a neighborhood when, really,
17 asking people what their interaction with their
18 neighborhood is and the extent to which it is
19 comforting or neutral or fear-producing is really
20 the element we ought to be looking at.

21 So, you know, and then I think, you
22 know, that we're stuck with how these elements

1 here are predictably more or less evident within
2 people we call duals or non-duals, which is
3 really, you know, it's an element of policy and
4 procedure rather than a personal characteristic.
5 So, you know, I think we've really got to attend
6 to the factors that really make this difference
7 between duals and non-duals. And those are,
8 those are personal characteristics that people
9 carry with them, and environmental
10 characteristics that are imposed on them.

11 And I just think that all this
12 commitment -- and I hear it again with the ASPE
13 stuff, and I'm not at all opposed to it -- but it
14 just, it works with existing variables. Large,
15 you know, large data sets that are already out
16 there that are rough proxies of these things that
17 are really important to people as people.

18 And I just think there needs to be a
19 lot of investment -- not in this top down, what
20 can we throw in the equation and see what it
21 predicts -- the working in projects that start at
22 the individual level that really understand

1 people's needs, characteristics, and elements
2 even of personality that make these outcomes all
3 important.

4 We know that those are the things that
5 really drive medical outcomes. And yet we seem
6 to be content to go back to the census data to
7 see what they can tell us. And they really just
8 don't tell us much about people.

9 So I think, you know, I think Clarke's
10 been saying this in, you know, 100 different
11 ways, but I just don't think we can overlook
12 that. That we spend our -- we give our hearts to
13 the person but we spend our money on these large
14 data sets that really don't, really don't
15 describe the person well enough to understand
16 what we're doing.

17 MEMBER BRINGEWATT: I want to agree
18 with both Charlie and Ross here. It seems to me
19 like this is reflective of the dilemma that this
20 group has had from the beginning in the sense
21 that we're constantly struggling with these are
22 the measures that are available. Of the measures

1 that are available, which ones do we think are
2 going to be most useful? And then we have this
3 huge gap question where I think most of us around
4 the room would say what's meaningful isn't
5 necessarily what's measurable.

6 And so how do we get at and incent and
7 help improve quality for duals with a limited set
8 of data that's not as meaningful as we would like
9 it to be, and at the same time know that there's
10 other things that are really important and that
11 we can't ignore? And I think part of our job
12 here is to find some balance, you know, between
13 those two issues.

14 And so I would suggest that while, you
15 know, I sincerely agree with you, Charlie, in
16 terms of what's most important, if we're working
17 with what's available, and from a research
18 standpoint there has to be some, you know, we
19 have to maximize validity and reliability, and
20 has to, you know, deal with sample size and data
21 that's available on a national basis, and it has
22 all of its criteria, you know, of the research

1 that has been done over the last couple of years
2 on social risk factors, the neighborhood one just
3 keeps popping up, particularly at that 9-digit
4 ZIP Code level as having the greatest
5 relationship to, you know, the effects of,
6 outcome effects of social risk factors.

7 So while it's limited, and I fully
8 share your perspective on that, I think, you
9 know, we have to run with the data that we have
10 available that's the best of the data that we
11 have available, recognizing its limitations.

12 MEMBER RAMONA: In looking at some of
13 this information, and certainly asking about
14 security -- and I'm not talking about armed
15 security but how we feel safe in our -- how our
16 patients feel safe in their community or home --
17 I kind of go back to that loneliness aspect. And
18 so I was wondering if anyone has experience or
19 knowledge of the short scale for measurement on
20 loneliness, three questions? And if there's any
21 way that we feel that would get to the questions
22 that are at hand or the concerns that are at

1 hand?

2 MEMBER ROSS: Well, both the National
3 Core Indicators and the Personal Outcome Measures
4 ask the individual of their perception of
5 loneliness, isolation, connectiveness, this
6 important domain of a series of questions. And
7 as Charlie's been working with the team that's
8 been revising those for over 20 years to get the
9 questions as correct as one can get them.

10 So that's one example in the area of
11 intellectual developmental disability, a little
12 bit of mental illness now in ageing and physical
13 disability, to get to that area that you've asked
14 for. So, again, this is, maybe ASPE can do this.
15 This, you know, this requires a huge amount of
16 research to crosswalk these multiple existing
17 measurement systems and try -- and everybody's
18 selling their measurement system -- to try to
19 figure out what's the best way of asking that
20 question and the most cost-efficient way so
21 people will actually use it.

22 MEMBER RAMONA: Yeah, this measure

1 does indicate that it's been tested both for in-
2 person and telephonic proxy, some proxy
3 information. And getting to not just the idea of
4 physical isolation but actual social aspects of
5 it.

6 CO-CHAIR MONSON: The only thing that
7 I would add to this conversation is it does feel
8 like there's a point at which we're not
9 collecting all the data we need to collect, not
10 necessarily measures but some data elements,
11 right. There's some key data elements, we could
12 probably debate exactly what they are, but my
13 guess is we could probably come up with five key
14 data -- key data questions or forms of questions
15 we should be asking.

16 And some of that problem is that we
17 don't want to have data burden on physicians or
18 other actors in the system. And then survey data
19 is great but it's survey data, so it's not 100
20 percent.

21 And so I do wonder, I mean as kind of
22 back to the measure developers, duals by

1 definition all have regular touch points with the
2 system. Right? With the Medicaid office. I
3 mean there's a Medicaid office. They have to get
4 their eligibility re-upped every year, or on a
5 regular basis, each state's a little different.

6 So, I mean there is, I mean it's just
7 something for us to think about that there are
8 some questions that could be -- some data that
9 could be collected at that point at the system
10 level. And so I think that we haven't talked
11 about that at all, that there's information that
12 could be gleaned outside of the medical system,
13 right, and these regular touch points that we
14 have, so that would just be the one thing that I
15 would contribute.

16 Yes?

17 MEMBER ROSS: So, the National Core
18 Indicators and the Personal Outcome Measures, the
19 whole focus is extended interview of each
20 individual person and their family. And years
21 ago as a result of this process I took, I
22 introduced them to the NCQA. And NCQA said,

1 we're not going to do this. Our plans aren't
2 going to do this, they're not going to invest the
3 money to do the kind of time-intensive person-to-
4 person engagement in order to learn about the
5 real individual, and then build a system around
6 them.

7 And so that's the reality is NCQA was
8 clear, we do what the health plans want us to do.
9 We try to improve it, but that's what we do. And
10 we're not going to advocate time-intensive.

11 And so we, we can get information, a
12 lot of ways of doing that, but who's going to pay
13 --- we're not willing to pay for that yet.

14 CO-CHAIR MONSON: Well, that's what,
15 I think that was where I was going is that
16 there's multiple pathways. So, first of all, we
17 would say, I think we think the NCA -- NCI --
18 national indicators both for individuals with
19 intellectual disabilities and the AD one for
20 ageing disabilities, lots of states are starting
21 to use it. We're very supportive of that.

22 And it is, it is an expensive venture,

1 right? CAHPS is going to be expensive too --
2 we'll talk about that in a little bit -- to do
3 in-person interviews.

4 So from a health plan perspective that
5 would be, that's what you've heard me say it,
6 beat that drum too, which is these comprehensive
7 assessments. We spend a lot of money as a
8 society, it's not just health plans, but we're
9 getting paid to do it, to collect this
10 information. Now, it's not going -- we can't,
11 it's not going to be -- we can't ask every
12 question that NCI-AD would ask because some of
13 them it's not appropriate for us to ask and we're
14 not going to get the right answer. But we can
15 ask a lot of them, right? We do ask a lot of
16 them, right? We do already.

17 And we all have responsibilities
18 around person-centered care planning, which is
19 the same idea. So this is where we're not using
20 the data we already collect. But not everyone is
21 in a health plan either.

22 So that was where I was going.

1 There's other places that we want to catch it.
2 But I think that we just need to be smart about
3 how we collect the information. I mean a part of
4 what's happened is that there has not been --
5 there are no standards on the Medicaid side,
6 right, that require common questions to be asked.
7 Each state's a little different. Some states
8 have a common form that plans have to use, some
9 states don't.

10 And so without some common -- and then
11 even in the states with the common assessments
12 across their state they could be different from
13 state to state. Now, some states are using NRI a
14 lot more. Right? I mean there's movement but
15 there is an opportunity to say, for measure
16 developers to say, look, states, you know, if you
17 want to use these types of measures then make
18 sure these questions are asked, right. And these
19 are the questions.

20 So I do think we could, I think we
21 could tap that system. And it shouldn't cost us
22 any more than we have today.

1 I think Alison was first, and then
2 Rich, and then Charlie.

3 MEMBER CUELLAR: I guess looking at
4 our homework response list I'm encouraged that
5 the follow-on report that they mentioned for ASPE
6 will be addressing residential community context,
7 and socioeconomic position and income. So the
8 report they did was a horse race against the 9-
9 digit ZIP Code versus the duals flag. And the
10 dual flag performs better. And now they're going
11 to use survey data to, it sounds like do a
12 similar exercise. You know, what about more
13 fine-grained, individual area income, kind of
14 what, which metric would we need to invest in to
15 improve on the dual flag or the 9-digit ZIP
16 Codes.

17 I'm encouraged by that. I didn't hear
18 much that would address, number one, the social
19 support, loneliness. I mean they talked about
20 functioning and trying to go someplace with
21 claims on that. So that, that's a little
22 disappointing. But I am encouraged. We'll just

1 have to see -- I mean the studies so far have
2 only used 9-digit ZIP Codes as they were
3 constrained, just like the first ASPE reports.
4 And now are they going to make a pretty large
5 investment and dig, dig deeper.

6 And I, you know, we'll learn a lot
7 from that. I mean it certainly -- and I don't
8 know to what extent the group feels that the
9 message has come across to say that subgroup
10 reporting by duals is really important. Not just
11 whether the measure is appropriate for dual
12 population, but whatever that measure is they
13 have measure upon measure upon measure, where
14 just reporting it by subgroup is really important
15 and to put that information out there.

16 MEMBER BRINGEWATT: Thinking about,
17 you know, where does this discussion go and what
18 are the next steps relative to this, and we go
19 away after this meeting, so what is it that we
20 recommend as it relates to this issue? You know,
21 in representing the SNP Alliance, I can tell you
22 that from a performance measurement standpoint

1 our members see this as the number one priority.
2 There's nothing in serving duals. 85 to 90
3 percent of special needs plans are duals. And we
4 also represent Medicare-Medicaid plans.

5 And this is their number one
6 performance issue. And there's two aspects of it
7 that are important to them. One is improving
8 quality care, regardless of what the measures
9 are. You know, so there needs to be
10 responsibility and accountability to address the
11 influence of social risk factors on health and
12 health outcomes. And, you know, we need to work
13 at that.

14 At the same time, there needs to be
15 more progress made on recognizing the effects and
16 measuring the effects of risk factors on health
17 and health outcomes.

18 And so I think kind of at the highest
19 general strategic level of recommendation, you
20 know, might be that, you know, indicate to CMS
21 this is an important area, please elevate the
22 importance of this within your overall

1 performance measurement strategy to the Quality
2 Forum itself. This is an important area for
3 duals going forward. So if there isn't a Dual
4 Workgroup, you know, there is a focus on these
5 issues that are really important to duals. And
6 so that becomes another place for addressing
7 these factors.

8 A third might be that we recognize the
9 interdependence of social risk factors with care
10 complexity. And, you know, so things like
11 frailty and disability, certain kinds of
12 disability and comorbidity, et cetera, it seems
13 to me like the National Quality Forum perhaps
14 could look at a strategy where there's more focus
15 on those kind of population-based performance
16 measurement issues that are cousins, if you will,
17 to dual social risk factors.

18 And that might be another place where
19 we could have some recommendations without
20 drilling down into some specific recommendations
21 as to what the, you know, we think the measure
22 developer should do.

1 We can have a discussion about those.
2 I think the discussion itself is useful. But I
3 think we would be remiss if we didn't at least
4 have some kind of focused recommendation of the
5 importance of this going forward, you know,
6 since, particularly since Dual Workgroup is going
7 to be going away.

8 MEMBER LAKIN: Well, I just want to
9 follow up on what Rich says. You know, I think
10 this is all about improving quality. And there
11 are different directions to approach that.

12 I think we, we should be committed to
13 measures that are not just good for assessing but
14 are also good for improving quality. And I don't
15 think we've talked a whole lot about how these
16 measures can do that.

17 Just to kind of return to that
18 loneliness thing, which over time I've just
19 become really attracted to because I think it's
20 sort of one of the most debilitating human
21 emotions, just to feel like you're not connected
22 to other people. And as we've looked at it, you

1 know, I mentioned that being afraid in your home,
2 being afraid in your neighborhood is really
3 connected to loneliness. Contact with family and
4 friends, things like that, you might predictably
5 see.

6 But also, you know, the environment
7 that one lives in, you know, whether you live
8 alone, whether you live with a family member,
9 paradoxically is less associated with loneliness
10 than being put in a congregate care setting where
11 loneliness is much higher, at least among the
12 15,000 people in the NCI data sets that we've
13 had.

14 So, you know, it seems to me that
15 people have learned from those things. In
16 Kentucky they really went on a rampage to reduce
17 the use of pharmaceuticals for people in their
18 developmental disabilities program because they
19 noted their rates were much higher than other
20 states.

21 So these things can create learning
22 environments I think that are terribly, terribly

1 important. But it doesn't happen when it's one
2 agency kind of doing it, you know, over the --
3 doing it to agencies, it only happens when it's
4 integrated into what people are doing. And,
5 again, that's why I think a commitment to how we
6 do all this stuff that we do to an organic effort
7 to begin with people and what's important to
8 them, and what we know is important to them, to
9 build measures that begin to include what we can
10 of what's important to people, is really
11 important.

12 And, you know, I hope, I hope as --
13 and I know it will -- as this world continues to
14 evolve, with or without NQF, that's a movement
15 that will not be suppressed. But it would be
16 nice if we could find ways to support it through
17 federal commitments.

18 MEMBER PARKER: Well, I certainly
19 agree with Charlie and what Rich just said. But
20 I wanted to go back to a technical point I think
21 Alison was making about the ZIP Code versus the -
22 - so this is like a minor thing compared to what

1 you guys are talking about, right? -- ZIP Code
2 versus dual status. My understanding is that the
3 issue is that you put them together and they're
4 much more powerful. So one enhances the other
5 and so it's not an either/or, it's like mix them
6 together, you know, and use them together, that's
7 what really counts.

8 MEMBER CUELLAR: I think in the report
9 the dual ones dominate.

10 MEMBER PARKER: Yeah. But there's
11 been other research that's been done on the
12 duals, using dual factors. But then adding the
13 ZIP Code, the 9-digit ZIP Code, and that's shown
14 more powerful results, is what I'm saying.

15 So I just wanted to make a point, but
16 I don't want to disrupt the flow of this.

17 MEMBER FOX-GRACE: So I just wanted to
18 pick up on what so much of the discussion which
19 is, okay, so after today where do we think this
20 should go, where should this discussion go? And
21 so for me, and both have been mentioned, but I
22 just want to kind of come back to it.

1 So, I think tomorrow the two things
2 that would need to happen is in order for this
3 work to continue since we're going on hiatus for
4 however long, is I do really like Charlie's
5 opening statement that he made yesterday which is
6 I think, Stacey, if you could go back and create
7 kind of an interdepartmental, you know, --

8 MEMBER LYTTLE: I'm on it.

9 MEMBER FOX-GRACE: Yeah, on it? Okay,
10 good.

11 It's been very powerful in the
12 disability community when all those different
13 agencies come together. And so, since we can't,
14 I think you all can.

15 And then, also, I think for NQF, I not
16 only think you should but I don't think you have
17 a choice, I do think you are going to need to
18 look for other funding sources. And so Jennie
19 mentioned, actually, a very good foundation, SCAN
20 Foundation. And there are many, many others:
21 Robert Wood Johnson, this Commonwealth -- I mean,
22 there are lots of them. And I just think we're

1 in that reality. And it's kind of a bummer
2 because now you've got to write grant proposals
3 and all of that.

4 But I just think it's -- well, I'm the
5 daughter of a CPA, and diversify has been what
6 I've always been taught. So I think no matter
7 what, it's smart, even if the federal funding,
8 you know, does come back I think it's smart
9 anyway to diversify your revenue sources.

10 So, anyway, that would kind of be my
11 two tracks of where I think this probably needs
12 to move on. Thanks.

13 MEMBER LYTTLE: I jokingly said I'm on
14 it. But I think you're exactly right. Deb
15 mentioned yesterday how, you know, we talk about
16 different agencies and then you get to CMS and
17 there's CMCS and CM and MMCO, and I think we
18 recognize the need for that coordination. Which
19 is why MMCO exists, because for years there was,
20 you know, there were the two things.

21 And I think over the past few years,
22 several years, we have tried to make some forays

1 into making that communication happen. And have
2 tried to do it first within our agency and then
3 beyond. So, you know, Deb and I actually have
4 talked before, and didn't just meet today or
5 yesterday, about various things. We probably
6 should talk more. And I think we're still in
7 HHS. But then beyond that, because there are
8 other agencies that still influence care for this
9 population.

10 And I think we, we are aware of that.
11 And so it's not, it's not lost on us when we hear
12 it again that it's definitely a necessity for
13 actually improving quality that we can't, you
14 know, sit in our offices and never talk to anyone
15 else.

16 So, I was joking, but I was also
17 serious.

18 CO-CHAIR MONSON: Tom, you can have
19 the last word. No pressure.

20 MEMBER LUTZOW: You know, it sounds
21 like we're sort of talking to ourselves and maybe
22 trying to talk NQF into going to the other side.

1 And, you know, going to the other side is, I
2 think that's what, that's -- we haven't gone to
3 the other side. And that's the biggest source of
4 dissatisfaction when we know these conditions
5 have an impact on quality and cost on the medical
6 side. Somebody's going to have to do this
7 because this vacuum is going to get filled by
8 somebody.

9 And it could be NQF or it could be
10 somebody else. The danger, of course, and I have
11 to believe there's a segment within the halls of
12 CMS that's fearful of this because expectations,
13 expectations created by measures create the
14 demand for funding. And so expectations, you
15 know, unfunded expectations tend to be a source
16 of pressure.

17 That being said, that being said, NQF,
18 or whoever does this at a national level is going
19 to have a bully pulpit. And gradually migrate
20 over time other funding sources, other than CMS
21 funding sources on the social service side to
22 recognize these as legitimate, holistic,

1 integrated kinds of views. And I think that
2 bully pulpit can over time work to join the
3 resources together toward a common purpose.

4 So we shouldn't really be afraid of
5 it. CMS shouldn't be afraid of it that now
6 they're going to be dragged into funding a bunch
7 of stuff that really has social service content
8 instead of medical content. But, you know,
9 unless you cross over you are not going to save
10 money on the medical side. You have to do this
11 in a responsible way, probably unfunded. But
12 that doesn't mean you don't create the
13 expectation that if loneliness shows up in the
14 assessment as a need, it is in the plan of care
15 and the expectation on the part of plans, ACOs as
16 well as plans, is to deal with it in some way.
17 You have to deal with it.

18 Now, we have to be careful, ACOs,
19 plans, we can't sell for poverty, we can't sell
20 for the high school dropout rate, you know, we
21 can't sell for that. So understand, you know,
22 Clint Eastwood was right, a man has to understand

1 his limitations, so we do have to understand our
2 limitations. But we need to begin to create the
3 crossover expectation, I think, for us to be
4 successful.

5 MS. MUNTHALI: I'll be quick.

6 Just wanted to thank you for this
7 discussion. We are recognizing the need to
8 diversify. I know a couple of people mentioned
9 partnership with organizations like the SCAN
10 Foundation. We actually did some work with SCAN.
11 So on a small scale we're doing this.

12 I think it's important to recognize
13 that while we are trying to diversify, make sure
14 we get to the right measures. CMS is probably
15 the largest developer, funder of development,
16 measure development. And so we need to be
17 cognizant of that. We are looking to other
18 partners to make sure we get the richness of
19 data, data elements, everything we talked about.
20 But it's going to take all of us. We're thinking
21 us at NQF, CMS as well, and these organizations
22 and trying to find how we can find, you know,

1 that middle ground where we come together.

2 And as much as we are a multi-
3 stakeholder organization, we are committed to
4 doing that. I have some ideas already on how we
5 have the relationships with developers, and it
6 might be good to kind of put something like a
7 consortium together of a group like this to help
8 measure development earlier.

9 When Stacey talked yesterday about
10 development, I was like, well, why don't you come
11 to this group to get technical assistance. This
12 is what we do. We would love to inform the
13 development of measures earlier on in the process
14 so they don't come to you if you're looking at
15 measures and these are not the right ones that we
16 need.

17 So, we think there's opportunity. It
18 might be different for all of us. But we're
19 committed to rethinking the way we do business.

20 CO-CHAIR MONSON: All right. We are
21 going to take -- Quickly, Alice Lind, you're on
22 the phone; correct?

1 MEMBER LIND: Yes, I am.

2 CO-CHAIR MONSON: Do you have anything
3 to disclose? I'm sorry. That's not a nefarious,
4 your disclosures of conflict of interest.

5 MEMBER LIND: Nothing to disclose.

6 CO-CHAIR MONSON: Thank you.

7 All right, a 15-minute break. We'll
8 be back here at 20 to 12:00 Eastern Time.

9 (Whereupon, the above-entitled matter
10 went off the record at 11:24 a.m. and resumed at
11 11:42 a.m.)

12 CO-CHAIR MONSON: All right, Erin,
13 you're on.

14 MS. O'ROURKE: Perfect. Thanks so
15 much, everyone. I'm Erin O'Rourke. I'm one of
16 the senior directors here at NQF, and I am
17 supporting the work of our Disparities Standing
18 Committee. And I wanted to give this group an
19 update on our trial period for risk adjustment
20 for socioeconomic and other demographic factors.
21 We abbreviate that to SDS.

22 So, I can skip a few slides since this

1 background was covered better than I could by
2 Karen and her team at ASPE.

3 But so just to give you some of the
4 NQF-relevant details. So just about two years
5 ago we began a trial period where NQF would allow
6 measure developers to bring forward measures that
7 included social risk factors in their risk
8 adjustment models. Prior to that, our criterion
9 policy prohibited the inclusion of such factors,
10 and only allowed developers to include clinical
11 factors that were present at the start of care in
12 their models.

13 So, during the trial period we lifted
14 that ban, if you will, and allowed developers to
15 bring forward measures that were potentially
16 adjusted. And we implemented the guidance of our
17 panel, which was actually now back in 2014, the
18 Risk Adjustment Expert Panel's recommendations
19 related to the appropriate use of social risk
20 factors.

21 So a little bit about how we're
22 operationalizing this. Each measure must be

1 assessed individually to determine if SDS
2 adjustment is appropriate. Not all outcome
3 measures should be adjusted for SDS factors. The
4 Risk Adjustment Panel was explicitly clear on
5 this.

6 For example, they used central line
7 infections would not be adjusted. There needs
8 to be both a conceptual basis, so that is a
9 logical rationale or theory, as well as empirical
10 evidence to do these adjustments. And the
11 recommendations applied to any level of analysis,
12 including plan, facility, and individual
13 clinicians.

14 So, during the trial period we had the
15 standing committees that are evaluating measures
16 that have been submitted for endorsement, in
17 charge of really looking over those measures to
18 determine as part of the endorsement process
19 whether the adjustment for SDS factors was
20 appropriate. We asked the committees to consider
21 both the conceptual and empirical basis for
22 adjustment, utilizing standard guidelines for

1 selecting risk factors.

2 If SDS adjustment is determined to be
3 appropriate for a given measure, we do endorse
4 one measure with specifications to calculate the
5 SDS adjusted measure as well as stratification of
6 a non-SDS adjusted measure. As recommended by
7 the panel, these specifications for
8 stratification should always accompany an SDS
9 adjusted measure.

10 We want to ensure there's
11 transparency. One of the main concerns when we
12 implemented these recommendations and started the
13 trial period was doing these adjustments could
14 worsen disparities, mask them, adjust them away
15 if you will. So --

16 CO-CHAIR MONSON: Erin, what's the
17 difference between -- what do you mean by some
18 are stratified but non-adjusted?

19 MS. O'ROURKE: Sure. So, the adjusted
20 measures basically bake in the calculation for
21 the social risk factors in its risk adjustment
22 model. The stratification does not include those

1 factors in the risk adjustment model but, rather,
2 lets you break apart each group. So if you had a
3 measure adjusted for, say, dual eligibles, in the
4 risk adjustment model it would just basically not
5 show you the difference. It would already pre-
6 calculate the impact that dual eligibility would
7 have on that person's outcome or their risk of,
8 say, being readmitted.

9 The stratification would let you break
10 it down by subgroup so you could see what was the
11 rate for people who were dually eligible versus
12 non-dually eligible.

13 Hopefully, Elisa, did I get that?
14 It's one of those things as soon as you try to
15 put it into plainer English you worry about
16 losing meaning. So, hopefully that helps a
17 little.

18 MEMBER CUELLAR: I think they came up
19 with a phone call where they say they're moving
20 to the term subgroup reporting. And you can do
21 that on an adjusted or unadjusted basis.

22 CO-CHAIR MONSON: Right.

1 MS. O'ROURKE: That's a great term.
2 We should probably move to that. It makes more
3 sense.

4 So to really address this concern
5 about worsening disparities, NQF brought together
6 a Disparities Standing Committee. They have a
7 number of items that they are charged to do.

8 The first is to develop a roadmap for
9 how measurement and the policy levers associated
10 with it can be used to actively eliminate
11 disparities. So, to kind of piggyback on what
12 Karen and her team were presenting, one of the
13 main things they're working on now is to really
14 think about what that plan for equity measurement
15 could look like. What topics would you want to
16 measure to really promote equity and start to
17 reduce disparities.

18 And then the next step when they come
19 back together in June will be to think about how
20 we can push to get those measures into use to
21 make equity a key focus in things like public
22 reporting programs, value based purchasing, to

1 try to capitalize on some of the shifts around
2 payment that are happening.

3 We also asked the Disparities
4 Committee to help us oversee the trial period and
5 to provide guidance. We've been giving them
6 periodic updates over the past two years. They
7 are also asked to provide a crosscutting emphasis
8 on disparities across all of NQF's work. So, as
9 we move to the conclusion of the 2-year trial
10 period we'll update the committee during their
11 June meeting and get their guidance on a
12 potential path forward here.

13 They actually were just meeting Monday
14 and Tuesday. So we presented them our evaluation
15 plan, what kind of data we could put together to
16 support their recommendations, and see if there
17 was anything else they thought we should look at
18 as we start to make potential recommendations
19 around whether we should make this a permanent
20 change in policy, if we should extend the trial
21 period, or we should put that ban back in place
22 and, you know, that looking at social risk

1 factors and risk adjustment models is the wrong
2 way to go.

3 So we have asked the standing
4 committees to consider a few key questions when
5 they're looking at SDS adjusted measures. First,
6 we asked them to look if there's a conceptual
7 relationship between the factor being considered
8 and the focus of the measure.

9 Was that risk factor present at the
10 start of care, is there variation in the
11 prevalence of that factor across the measured
12 entities?

13 Do the empirical analyses, that is the
14 ones provided by the measure developer, show that
15 the social risk factor has a significant and
16 unique effect on the outcome in question?

17 And is the information available and
18 generally accessible for the measured patient
19 population?

20 So, I did want to update you all on
21 some of our findings to date. This is still
22 really just at the start of gathering our data

1 and evaluating what's happened over the past two
2 years. So there will be more information to
3 come, but a little sneak preview, if you will, of
4 what we've been finding.

5 So, as I was saying, since April 2015
6 we have asked all of our standing committees to
7 consider the potential role of SDS factors in the
8 evaluation of all submitted measures, with a
9 particular focus on outcome measures.

10 We also had the Readmission and the
11 Cost and Resource Use Standing Committee go back
12 and take a look at some measures that were
13 endorsed with the condition that the developers
14 perform some additional analyses to determine if
15 there was a need for the inclusion of SDS factors
16 in their models. Those measures were endorsed
17 immediately prior to the start of the trial
18 period, and the potential need for SDS adjustment
19 had been a big theme in their endorsement
20 reviews.

21 So, ultimately, the board of directors
22 put this condition on their endorsements. So we

1 worked with the developers to bring them back in
2 and do some, some additional work around there to
3 determine the impact of these factors.

4 So, probably not a shock to anyone
5 given your conversation this morning and what
6 Karen presented, we've had a significant number
7 of measures come forward with a strong conceptual
8 basis for SDS adjustment. However, when you look
9 at the empirical analyses to support whether or
10 not you put that factor in your risk adjustment
11 model, frequently it just hasn't been there. It
12 doesn't change the performance of the risk
13 adjustment model. It's a very, very tiny effect,
14 so developers have chosen to leave it out, given
15 some of the politically charged nature around
16 this topic.

17 To date, we've actually had a
18 relatively small number of measures that have
19 been endorsed with risk adjustment for SDS
20 factors. Some examples are we have a patient
21 reported outcome for pediatric experience of care
22 that is survey-based and takes into effect the

1 caregiver's education level to the person
2 completing the survey.

3 We've also had some measures in the
4 nursing home setting. One around hospital
5 readmission and one about discharge to the
6 community that look at things like payer mix and
7 marital status, so as a proxy for caregiver
8 availability.

9 And, whoops, I had the same bullet
10 twice, apologies there.

11 So, again, really just to tack onto
12 the conversation this group's already been
13 having, we've really found there's very limited
14 availability of patient-level data. We've had
15 developers do some extensive work to get to 9-
16 digit ZIP Code. But it's not easy to do and not
17 really readily accessible.

18 Risk models using currently available
19 SDS adjusters are not demonstrating an
20 association for measures that have a clear
21 conceptual basis.

22 MEMBER CUELLAR: Can you clarify?

1 What do you mean by the first point? The data
2 are available as long as we have the ZIP Code.
3 Is it the fact that the ZIP Code, 9-digit ZIP
4 Code isn't available? Because the other thing's
5 been constructed and you can just download.

6 MS. O'ROURKE: Sure. So basically
7 getting to that 9-digit ZIP Code has been
8 challenging. And when they did the 5-digit
9 analyses it was just not granular enough.

10 MEMBER CUELLAR: I'm not understanding
11 that. The 9-digit data are available. That
12 census data has been constructed. So is it that
13 they don't have the patient's 9-digit?

14 MS. O'ROURKE: So, the work to match
15 it, yes, to get to the patient's -- to match the
16 patient to their 9-digit ZIP Code through the
17 claims data.

18 MEMBER CUELLAR: Well, they don't have
19 an address? Okay, the problem is that many times
20 they don't have an address?

21 MS. O'ROURKE: Yeah.

22 MEMBER CUELLAR: So maybe that's what

1 we're talking about.

2 MS. O'ROURKE: Yes. Some, yes, that's
3 a better way to --

4 MEMBER CUELLAR: It sounds like we
5 don't have the 9-digit ZIP Code census block
6 data. But that's the piece we do have?

7 MS. O'ROURKE: Yes. So that is
8 available. And we've had developers use things
9 like the AHRQ SES index to get to that and then
10 try to match that with what's in the claims data.
11 But it's proven to be quite a lot of work to get
12 that match done. And --

13 MEMBER CUELLAR: Because they don't,
14 and the claims don't have the 9-digit ZIP Code?

15 MS. O'ROURKE: I believe that is the
16 issue, yes.

17 MEMBER CUELLAR: It would have to be.
18 Because if they're arguing we don't have census
19 data down to the 9 digits, I can download that
20 for them in about 20 minutes. Right?

21 MEMBER POTTER: Not everybody has the
22 ability to process on 50 million records. That's

1 really the problem.

2 MEMBER CUELLAR: Right, but I don't
3 think that's -- the bullet's not capturing the
4 issue. Either it's that you don't have the
5 address, which means you don't have a 9-digit ZIP
6 Code, or it's that you don't have the
7 computational power to merge on, you know, a few
8 more variables.

9 MEMBER POTTER: But I think the issue
10 of it not being easily accessible is a legitimate
11 issue. I mean, if we were merging at the county
12 level as opposed to the 9-level ZIP Code, there's
13 a whole database that HRSA puts out called the
14 Area Resource File which has all kinds of stuff
15 at the county level. And it's readily available.

16 This isn't readily available, you
17 know.

18 MEMBER CUELLAR: Well, but it could
19 easily be, since it has been constructed, it
20 could easily be made available. And if that's
21 the -- if it's the computational power of, gee,
22 now I've got to merge it on, that's no different

1 from merging on the Area Resource File
2 conceptually. If your programs can do one, they
3 can do the other, if the computers can. I mean,
4 I'm not saying they all can.

5 But then it's a can we make this 9-
6 digit ZIP Code file with the census information
7 more accessible? That we could do.

8 MEMBER LYTTLE: Without having to pay
9 for it.

10 MEMBER CUELLAR: Right. Right.

11 MS. O'ROURKE: So we've also heard
12 some other concerns about the factors that
13 developers have selected and analyzed. Some of
14 the proxies that they've been using to get to a
15 person's actual socioeconomic status and their
16 social risk have not really been adequate.
17 They're just a little too blunt to show a
18 person's actual -- I think Charlie put it very
19 well -- the data versus the person issue.

20 We also had a lot of push back from
21 some of our stakeholders about when developers
22 have included race as a potential variable. We

1 have not adjusted any measures with race in their
2 final risk adjustment models. But it's been a
3 pushback from stakeholders that developers have
4 even looked at that.

5 We took it to our Disparities
6 Committee for some more guidance there, and they
7 came down more along only really if there's a
8 genetic basis, emphasizing it should not be a
9 proxy for socioeconomic status.

10 We've also heard from some of our
11 stakeholders a call for a more prescriptive
12 approach to how developers are testing these
13 variables. For some background for those of you
14 that haven't been involved in our endorsement
15 committees, NQF does not tell developers what
16 methods to use to test their risk adjustment
17 models. We also don't give a standard set of
18 variables that they should look at. It's up to
19 them to make the decisions about those things and
20 for the standing committees to determine if they
21 agree or disagree.

22 We've heard some, some calls that NQF

1 should be a little more prescriptive in this
2 space, but that's how we approach both clinical
3 and social variables, so it's something to think
4 about.

5 I did want to bring forward a slide
6 that has some of the implication for your family
7 of measures. Gave an update on this last year,
8 so just to close that loop.

9 A number of measures in the family
10 were reviewed during the trial period, mostly all
11 dealing with readmissions. All maintained
12 endorsement without social risk factors included
13 in their models.

14 Let's skip that slide because I think
15 we're all familiar with it after Karen's
16 presentation.

17 But just to keep you informed on some
18 of the next steps here. The Disparities
19 Committee met earlier this week, provided some
20 feedback to us on the evaluation plan for the
21 trial period. We'll bring them back together in
22 June to share the results of the evaluation and

1 to get their input on what could be a path
2 forward here.

3 Similarly, we'll take it to our
4 Consensus Standards Approval Committee in July
5 for any thoughts that they might have. And then
6 in July the board is tasked with determining what
7 should be our path forward here.

8 CO-CHAIR MONSON: Erin, can I go back
9 and ask a question?

10 MS. O'ROURKE: Of course.

11 CO-CHAIR MONSON: So, on those five,
12 or the ones that you looked at when you said that
13 there was no -- so I'm just reflecting on the
14 prior conversation where dual status alone seemed
15 to have a major impact. Is there no adjustment
16 because you're using dual as a subgroup,
17 therefore within dual? Or is it there's no
18 adjustment for dual/non-dual status?

19 MS. O'ROURKE: No adjustment for
20 dual/non-dual status.

21 CO-CHAIR MONSON: So why do you think
22 that is that the ASPE work shows something so

1 different than what you guys have been doing?

2 There's something that doesn't fit is what I

3 mean.

4 MS. O'ROURKE: I think you hit on the
5 million dollar question. We've heard a lot of
6 different potential reasons. Some developers
7 used whether it improved the C-statistic of the
8 risk adjustment model, so the, really the stat
9 you look at to see how well your risk adjustment
10 model is predicting outcomes as their metric for
11 whether they'd include or not include. And
12 anything that didn't improve that, they didn't
13 improve.

14 We've heard some concerns that some of
15 the developers looked at all of the clinical
16 factors first and then baked in things like dual
17 eligibility as a risk adjuster. So that by the
18 time you got to that, most of the risk was
19 accounted for by the clinical factors and you
20 just had a very small effect seen by dual status.

21 So, I think it's something we've
22 gotten pushback on from particularly the provider

1 community. And as Karen was saying, there's a
2 lot of evidence that there's something there, and
3 it's not showing up when developers do these
4 calculations.

5 CO-CHAIR MONSON: I think Alison
6 wanted to go first and then D.E.B.

7 MEMBER CUELLAR: Is it also possible,
8 given what you've said, that NQF doesn't impose
9 any methodology, that they didn't even test dual
10 as one of their factors?

11 MS. O'ROURKE: Yes. So not every --
12 you were not required to test dual.

13 MEMBER CUELLAR: What they would have
14 said is risk adjustment didn't matter, but they
15 may not have looked at dual versus non-dual.

16 MEMBER POTTER: There's also data
17 systems that don't adequately capture secondary
18 payers, which in this case is the duals. And so
19 when you're talking about clinicians and
20 hospitals, the primary payer is Medicare, and
21 then the hospital or the doctor would have to
22 have another variable that said they were also

1 covered by Medicaid and somehow captured that in
2 adjustment.

3 So, I think some of it is just
4 accessing the information at the clinician or the
5 provider level, which is different than what CMS
6 can do when it goes and looks at the enrollment
7 file and it has just one little variable it can
8 attach to a person that says they're dual.

9 CO-CHAIR MONSON: Tom.

10 MEMBER LUTZOW: I'm sure you have, you
11 know, a good statistical consultation. We
12 certainly have found that evaluating one factor
13 at a time may not be the right way to go because
14 these factors play -- they have
15 interrelationships, interactions behind the
16 scenes. So, hopefully, as you look at this,
17 these things are not got from isolation but
18 looked at in groups because as groups they may
19 have an impact. But I'm sure you're looking at
20 that.

21 MS. O'ROURKE: Yes, it's a good point,
22 how you look at things can have a significant

1 impact. And that's certainly something we've
2 heard from some of the stakeholders that are
3 telling us these measures should be adjusted and
4 we need to push harder here. So that's a good
5 input.

6 CO-CHAIR MONSON: Rich.

7 MEMBER BRINGEWATT: Yeah. I think
8 this is in part related to what often happens
9 when there's a self-evaluation done where the
10 measures used are defined by the person doing
11 their own evaluation, you know, and where there
12 aren't outside standards.

13 And I think part of what National
14 Quality Forum is about as it relates to provider
15 standards is that there is some standard relative
16 to whether the measure is adequately tested, and
17 what are the factors that were involved, and what
18 is the population mix that was involved? And
19 it's, you know, the National Quality Forum has a
20 very rigorous set of standards for whether it's a
21 good measure or not. And I think that and all
22 due respect to the people who have done these,

1 done the measurement, I'm not trying to cast
2 aspersions on anyone. But I think it's just good
3 scientific process that there be standards set
4 for testing of whether social risk factors are
5 adequately addressed in any of the measures used.

6 You know, we, that kind of standard is
7 applied to every other performance measurement
8 for providers, for plans. I think it should be
9 also used for the testing of the adequacy of
10 whether the measure includes or excludes
11 accounting for social risk factors.

12 CO-CHAIR MONSON: Alison.

13 MEMBER CUELLAR: I don't know that the
14 statisticians could ever tell you whether you
15 should adjust for a risk factor because the
16 implications are profound. Right? So, if you
17 serve a lot of duals, according to the ASPE
18 result, and your, let's say your quality was a 4,
19 if you serve a lot of duals they're going to
20 upweight it and it's going to look like a 4.2.
21 Right? Just sort of roughly speaking.

22 Whether you want to do that or not is

1 a policy decision; right? You're going to get,
2 right, it has to do with penalties one way or the
3 other, even playing fields, which playing fields
4 do you want to even out, which ones do you not
5 want to. Neither the Academy nor ASPE is telling
6 CMS whether or not they should do it, they're
7 just saying statistically would it even matter.

8 So, but none of them disagree with the
9 idea that one can report it separately by
10 subgroup. But that's innocuous. That's not
11 moving money from A to B or C to D in ways that
12 you may or may not -- they're tradeoffs. I mean,
13 everyone is very clear that there are tradeoffs.
14 There are tradeoffs. Once duals in an ASPE
15 report is statistically meaningful, then they
16 simulate would it have moved money to use? And
17 the answer is yes. Is that desirable is another
18 question.

19 So I don't think NQF alone is ever
20 going to be able to tell you you must do this
21 adjustment because it's going to depend on what
22 your goal is. It could tell you whether

1 statistically it mattered. And then NQF could, I
2 would think, say subgroup reporting makes sense
3 if statistically the duals group looks different.
4 And that's not going to move money from A to B,
5 it's just going to shine light on subgroup
6 differences that appear to matter in the
7 analyses.

8 So, I'm not exactly sure why the
9 subgroup's charge is to figure out whether we
10 should do the quality adjustment as opposed to
11 just give us some statistical information. And
12 if the statistical information is so
13 heterogeneous, it's very difficult to process.
14 It's like saying we have no definition of
15 validity, reliability, sensitivity. Just throw
16 any number you want at us and we'll review it and
17 assess. I mean I don't -- it seems a little odd.

18 MS. O'ROURKE: Great. So, I really
19 just wanted to get some input from this
20 committee, continue the conversation that you've
21 already been having previously and just now. As
22 we start to bring this to the Disparities

1 Committee is there any input or guidance you'd
2 like us to think about, particularly since dual
3 eligible status has been one of the most common
4 factors that our developers have tested? Any
5 thoughts on that? Arguments for or against?
6 Anything we should be cautious about?

7 MEMBER POTTER: I just have a question
8 really. Is there someplace where there's a list
9 of the measures? I mean, if we go to the QPS is
10 there a way to search and have the measures that
11 have this adjustment come up?

12 MS. O'ROURKE: It will be coming in
13 the future weeks ahead. We're actually wrapping
14 up our data collection process now, asking staff
15 to fill out all this data so that we can go
16 through things like QPS and perhaps create one of
17 our -- I forgot the term -- a portfolio of
18 measures that has that information for you.

19 So, stay tuned. It will be coming.

20 We're also doing some work around
21 trying to get out what variables were looked at
22 for each measure. You know, we want to be very

1 transparent here about what happened and get the
2 information out to you also. It's coming.

3 MEMBER CUELLAR: It would be helpful.
4 Even just to know whether or not they looked at
5 dual or not and with what other variables, and
6 then what methods they used.

7 MS. O'ROURKE: Sure. Yes.

8 CO-CHAIR MONSON: Pam.

9 MEMBER PARKER: Have they looked at
10 dual at all? And you said that might be
11 separately reported in some of them, or not?

12 MS. O'ROURKE: They should. If they
13 included it, they would have the instructions to
14 stratify so you could report that.

15 MEMBER PARKER: And does that mean
16 that the measure is used comparing the dual group
17 to another dual group? Or does it mean it's just
18 reported out like that?

19 MS. O'ROURKE: So, it would be how
20 it's endorsed. Unfortunately, we don't always
21 control how a measure is used. Someone could
22 choose to use what would be the non-endorsed

1 version that doesn't include a certain adjuster
2 or how they reported out. So, it's a
3 recommendation for how NQF would like to see the
4 measure used and what we've endorsed as the best
5 practice. But the decision about which version
6 of a measure to use really rests with the payer
7 or the purchaser group that's doing the
8 evaluation.

9 MEMBER PARKER: Well, I can see where
10 it might depend on the specific measure. But it
11 would, I would think it would be good to
12 encourage them to try to say whether or not, you
13 know, it would be appropriate to compare duals
14 against duals in that measure rather than duals
15 against everybody else. You know, if you're
16 going to stratify it and you're going to report
17 it out in that way, then that gives you that
18 opportunity. And so it would be good if they,
19 you know, if they utilized it in some way and
20 suggested that, so.

21 CO-CHAIR MONSON: Tom.

22 MEMBER LUTZOW: Yeah. I'm hopeful

1 that the guidance would maybe be adopted in terms
2 of testing for SES or social determinant impact.
3 I think we saw some measures yesterday, the HIV
4 measure, where the developer assured us that
5 there was no social development impact.

6 Rather than an assurance, it would be
7 nice to hear that we tested this against NCQA's
8 standards and it came up negative. Okay, now I,
9 now I believe that. But, hopefully that is a
10 product that you come out with.

11 CO-CHAIR MONSON: Rich.

12 MEMBER BRINGEWATT: Yeah. I, well, a
13 couple of things. One, in looking at the options
14 that are under consideration here, I think
15 they're reasonable options to consider because it
16 provides a good basis for discussion.

17 I would be extremely disappointed if
18 the decision was made to rescind, you know, no
19 longer go forth in doing this. This is a, you
20 know, to be fair to measure developers, this is
21 even though research on the effects of social
22 factors in health and health outcomes is well

1 established, you know, that has been demonstrated
2 in multiple ways for decades. Dealing with risk
3 adjustment or sorting out how to account for that
4 performance measurement is a relatively new
5 science.

6 And so I think at some level we have
7 to be cautious and careful about acting too
8 quickly. At the same time, I think we have to be
9 careful that we do in fact act because there's
10 clear evidence that there is an influence here.
11 And even in relation to all-cause hospital
12 readmissions, there are a couple of very, you
13 know, scientifically -- scientific studies that
14 show exactly the opposite, you know, that there
15 is, that social factors do influence the
16 reporting of all-cause readmissions.

17 And so, that raises questions about
18 methodology that I think are appropriate to ask
19 for an organization like the National Quality
20 Forum. Which drives me towards, you know, a
21 suggestion that there be more work done in this
22 area, that now is not the time to stop. But it

1 seems to me like, you know, there have been
2 minimum standards for what is necessary in
3 looking at other measures. Seems to me like
4 there should be minimum standards for the testing
5 of social factors in performance measurement.

6 And there's differences of opinion as
7 to what that should be. And that's appropriate.
8 But, you know, I think it would be remiss if
9 there wasn't some leadership provided, even if
10 it's a matter of guidelines and not a
11 requirement. You know, at least some leadership
12 provided on the part of the National Quality
13 Forum for addressing this issue in a
14 scientifically rigorous way. It is the quality
15 standard, so define the quality standard for
16 doing this.

17 MEMBER ROSS: Hi, Erin. I don't know
18 if you were here this morning. I mentioned but
19 could not remember the four major subpopulations
20 in the duals population that this committee
21 analyzed and studied in 2013 and 2014. But I
22 would just remind you and remind all of us, those

1 are official reports from the National Quality
2 Forum to CMS to go back and examine what we said
3 about those four.

4 We spent a whole meeting defining the
5 four and then we studied it for another year-and-
6 a-half. And I can't remember precisely, I could
7 guess but I can't remember precisely what the
8 four were.

9 I apologize, I didn't listen to the
10 Disparities Committee meeting Monday and Tuesday.
11 But previous meetings, the sole, single
12 disability expert on the committee was
13 disappointed. The National Academy of Medicine
14 concluded that disability was a product of but is
15 not a factor, a risk factor. And so the
16 representative previous to this week -- because I
17 don't know what happened this week -- was
18 disappointed that this Disparities Committee just
19 accepted the National Academy of Medicine
20 recommendation that we shouldn't really focus on
21 disability; it's a product and it's important but
22 it's not a risk factor. And the disability

1 field, obviously, would like that kind of
2 thinking further discussed.

3 MS. O'ROURKE: I think those are both
4 great points. I think to your first point,
5 that's a great suggestion to go back to those
6 reports and see what could be done about maybe
7 breaking duals down. If that, if that factor is
8 still too not getting granular enough, what could
9 be done to break that down.

10 So I can pull those and see what this
11 committee previously said.

12 For your point about Dr. Iezzoni's
13 strong feelings about the NAM report, that was a
14 prominent feature of discussion at the meeting
15 earlier this week. So we I think will have some
16 language in our reports perhaps challenging that
17 and suggesting potential different directions.

18 MEMBER ROSS: Thank you.

19 CO-CHAIR MONSON: Other comments?
20 Anything else you need from us, Erin?

21 MS. O'ROURKE: No, this was great.
22 Actually I was in the back listening for most of

1 the morning. And this has been really helpful
2 input. It was remarkable how well the
3 conversation tracked between this group and our
4 Disparities Group. So that gives me some
5 encouragement that we have some validity there
6 and we're on the right track.

7 So, thank you for all of your time and
8 input. And we'll be bringing this to our
9 Disparities Committee in June as they start to
10 think about what's our path forward here. So
11 thank you so much for your time this morning.

12 CO-CHAIR MONSON: Thank you, Erin.

13 I think we're going to go to public
14 comment.

15 MS. BUCHANAN: Yes, hi. Shawn, would
16 you mind opening up the lines so we can hear from
17 any members of the public. Additionally, if you
18 are not connected via telephone and you would
19 like to chat a question in your chat box, NQF
20 staff can read it aloud.

21 OPERATOR: And at this time if you
22 would like to make a public comment, please press

1 star then the number one on your telephone
2 keypad.

3 And we have no public comments at this
4 time.

5 MS. BUCHANAN: Thank you.

6 CO-CHAIR MONSON: All right. So we
7 are actually like a half hour ahead. But,
8 unfortunately, our next speaker is external so we
9 can't necessarily get them to move up faster. So
10 the bonus to that is there's a long lunch then.

11 So, we need to be back here, we're
12 going to start again at 1:15, 1:15 Eastern.
13 Enjoy lunch.

14 (Whereupon, the above-entitled matter
15 went off the record at 12:16 p.m. and resumed at
16 1:15 p.m.)

17 CO-CHAIR MONSON: All right. We are
18 reconvening, finishing lunch.

19 DR. ABERY: Okay.

20 CO-CHAIR MONSON: All right, guys.
21 We've all been guilty. So, we're sitting. We're
22 sitting. We're not chatting. We're listening.

1 Rachel is taking over -- or Kate is.

2 MS. BUCHANAN: Hi. Thank you very
3 much. And, Brian, I just want to make sure that
4 we can hear you.

5 DR. ABERY: Yes. This is Brian here
6 and Renata Ticha.

7 MS. BUCHANAN: Great. So, we just
8 want to briefly introduce Dr. Brian Abery, who is
9 co-director of the Rehabilitation Research and
10 Training Center on HCBS Outcome Measurement at
11 the University of Minnesota's Institute on
12 Community Integration.

13 And he is also the co-director of the
14 Institute's Educational Assessment and
15 Intervention Program.

16 And we'd also like to introduce his
17 colleague, Dr. Renata Ticha, who is a research
18 associate and a principal investigator at the
19 University of Minnesota's Institute on Community
20 Integration.

21 And if you all wouldn't mind just
22 saying "next," we'll move the slides along for

1 you. And with that, we'll take it off.

2 DR. ABERY: Okay. Well, thank you
3 very much. We appreciate the opportunity to
4 share the work we're doing with our Research and
5 Training Center on Home and Community Based
6 Services Outcome Measurement with you.

7 And we will try to stay within our
8 time limit today. I know I sent a lot of slides
9 and we're going to move through these fairly
10 quickly, but we wanted to give you some examples
11 of some of the learning that has occurred since
12 we began our project approximately a year and a
13 half ago.

14 Can we go to the next slide, please.
15 Although some of you may know a little bit about
16 our Research and Training Center, I just wanted
17 to introduce you to our primary partners before
18 we got into content.

19 In addition to the University of
20 Minnesota and our Institute on Community
21 Integration, we are working with Mark Salzer,
22 Gretchen Snethen and Beth Pfeiffer at Temple

1 University; with Steve Kaye from the University
2 of California-San Francisco; with John Corrigan
3 from The Ohio State University; and Joe Caldwell
4 from the National Council on Aging.

5 We are also working with a number of
6 the organizations that are involved in
7 administering HCBS outcome measurement programs.
8 And of course we're funded by NIDILRR.

9 Next slide. So, I'd like to begin by
10 just kind of letting people know that we are a
11 five-year research and training center.

12 And our goal was to undertake a
13 program of research that would really help us
14 collect and analyze the data necessary to be able
15 to report to a wide variety of end users,
16 specific measures related to HCBS outcomes and
17 quality that were both psychometrically sound and
18 could be used with multiple populations ranging
19 from individuals with intellectual and
20 developmental disabilities, physical and
21 psychiatric disabilities, traumatic brain injury
22 and age-related settings.

1 And we really wanted to focus on the
2 development of measures that could be used in
3 specific settings and contexts along with
4 relevant risk adjusters.

5 In addition to the development work we
6 are doing here, we're also providing training and
7 technical assistance to a variety of stakeholders
8 on outcome measurement in the HCBS field both in
9 Minnesota and nationally.

10 Next. Next slide, please. What I
11 really want to kind of focus on before we get
12 into the content, is the fact that, you know, as
13 we have thought about our research and were
14 developing our center, we really wanted to start
15 at Base 1 with the National Quality Forum's
16 framework and really take it out to stakeholder
17 groups, a variety of stakeholder groups
18 nationally and figure out, first, what they
19 thought was most important to measure.

20 We have in the NQF framework, what
21 experts in the field thought was most important
22 to measure. We really wanted to get out into the

1 community as our first step and find out what
2 those other stakeholders are thinking.

3 As a second step, we wanted to
4 identify gaps between the current measures which
5 are out there and available for use in both the
6 NQF framework and federal and state policy
7 operational drivers.

8 And then, to identify which measures
9 are currently psychometrically sound and robust
10 enough to be used across multiple populations.

11 And then, to really start a three-and-
12 a-half-year process that includes development -
13 field-testing to support the refinement and
14 development of new measures to get at those gap
15 areas.

16 Next slide, please. So, our goal is
17 not to create a master instrument. I mean, we're
18 not trying to replicate what, you know, other
19 groups who have national projects are undertaking
20 with respect to HCBS outcome measurement.

21 It was really to try to take
22 measurement in this area, kind of that next step,

1 so we could report to end users, you know, what
2 measures are psychometrically appropriate to use
3 with specific populations and contexts and
4 settings and with the eventual goal of NQF
5 endorsement in those areas that our stakeholders
6 indicated were most important and which we
7 identify gaps within.

8 Next slide. So, we have kind of
9 conceptualized our work over the five-year period
10 as consisting of six different studies.

11 Study 1 I've already alluded to;
12 soliciting broad stakeholder input on the NQF
13 measurement framework.

14 Study 2, which is also well underway,
15 is a gap analysis and we're taking a look at the
16 NQF measurement framework and current instruments
17 which are being used to measure HCBS outcomes.

18 Study 3 focuses on the identification
19 of high-quality/high-fidelity implementation
20 practices in HCBS measurement.

21 In Study 4, we'll be working very
22 closely with our colleagues at Temple in the

1 refinement and development of new measures.

2 Study 5 is a large-scale study focused
3 on kind of a national study to ascertaining the
4 reliability, validity and sensitivity to change
5 of the measures we have refined and newly
6 developed.

7 And then, finally, Study 6, which is
8 a little bit out of order there, which we're
9 already working on, is to identify and eventually
10 test in Studies 4 and 5, relevant risk adjusters
11 for home and community service-based outcomes.

12 Next slide, please. So, I'm sure all
13 of you are familiar with the National Quality
14 Forum framework. So, we can just kind of put
15 this slide up for just a minute or so with its 11
16 domains and two to seven subdomains within each
17 domain.

18 This was kind of our beginning point
19 of our research in Study 1. We can go through
20 the next two slides quite quickly just to give
21 the group -- you can see we have the slides that
22 focus on human and legal rights, service delivery

1 and effectiveness, workforce, system performance
2 and accountability. And the more individualized
3 outcomes, choice and control, community
4 inclusion, equity, holistic health and
5 functioning.

6 So, if we go to the next slide, we can
7 talk about our first study. And that really was
8 designed to gain the input of a critical set of
9 representative stakeholders from around the
10 country.

11 Next slide. What we are using for
12 this process is a group of stakeholders who
13 include individuals with disabilities across that
14 disability group that we are working with, family
15 members of persons with disabilities when that is
16 appropriate, providers, and program
17 administrators both at a state and national
18 level.

19 And, again, our disability populations
20 of focus were individuals with intellectual and
21 developmental disabilities, physical
22 disabilities, traumatic brain injury, psychiatric

1 disabilities and mental health challenges, and
2 age-related disabilities.

3 Next slide.

4 CO-CHAIR MONSON: Brian, can I just
5 interrupt for a second? This is Michael Monson
6 from Centene.

7 So, the one group I didn't see on
8 there, and I say this as a self-interested party,
9 was health plans.

10 Are you planning on incorporating them
11 as well?

12 DR. ABERY: I didn't catch that group.

13 CO-CHAIR MONSON: Health plans,
14 managed care organizations.

15 DR. ABERY: Oh. Yes, they were
16 actually part of our program administrator and
17 provider groups.

18 CO-CHAIR MONSON: Thank you.

19 DR. ABERY: So, we're using a process
20 that we have developed here at the University's
21 Institute called participatory planning and
22 decision-making. And I'm just going to quickly

1 kind of go through the process so you have a
2 feeling for what we did as part of this group.

3 In each phase of the process,
4 stakeholders are distributing ideas to the
5 framework --- to the NQF framework under
6 discussion.

7 They have the opportunity to add new
8 domains and broad domains, if they want,
9 subdomains. They can suggest the removal of
10 domains or subdomains they view as unimportant.

11 They then provide importance
12 weightings for each domain and subdomain. They
13 discuss their thinking while undertaking these
14 importance weightings. And then they do a second
15 round of importance weightings.

16 Following the weighting of both
17 domains and subdomains, we then are able to
18 determine proportional importance weights that
19 are assigned to each subdomain.

20 So, it's a very interactive process
21 that takes about two to two-and-a-half hours to
22 implement.

1 Next slide, please. And we basically
2 did our implementation with 54 groups over the
3 course of the first year-and-a-half of the
4 project, including over 280 participants.

5 We have three more groups left to
6 collect. But, again, those groups cut across
7 nationally all of those --- all of those
8 stakeholders that we previously discussed.

9 You can see from the next slide, which
10 is just a map of where our participants resided,
11 number of groups conducted on the east coast, but
12 we ended up trying to get groups in both rural
13 and urban areas across the U.S.

14 The next slide shows our disability
15 population. I'm not sure whether that's going to
16 come up large enough for you to really see. But
17 as you can see, we cut across all of those groups
18 that we are responsible for as part of our
19 Research and Training Center.

20 So, the measurement framework question
21 that we really wanted to ask in this study, was
22 which NQF domains and subdomains were viewed by

1 our various stakeholder groups as most important
2 to measure, what if there were differences
3 between our stakeholder groups and disability
4 populations and how they prioritize those
5 domains, and really to look at the extent to
6 which the stakeholders supported the current NQF
7 framework as including everything that they
8 thought was a critical importance to measure and
9 looking at HCBS outcomes.

10 Next. So, this next slide just gives
11 you an indication of our importance weightings
12 across the various domains of the NQF.

13 Those numbers on the right-hand side
14 include both the importance weightings, which are
15 weighted on a zero-to-100-point scale for most
16 groups and our standard error.

17 And as you can see, the individuals
18 who were part of the NQF group that developed
19 the framework, you know, basically hit the nail
20 on the head, so to speak, in that all of the
21 basic domains that were identified by the group
22 of experts were considered by our stakeholders

1 across the country, across these disability and
2 stakeholder groups, as to the importance.

3 When we looked at the subdomains,
4 there were some additional differences. And we
5 can talk about those in just a minute.

6 Next. We took a look at both the
7 domain and subdomain level using multi-analysis
8 variants, to really take a look at whether
9 domains were evaluated in a similar manner by
10 disability population and stakeholder type using
11 both a full factorial design and some post-hoc
12 comparisons to really see whether we had some
13 significant effects at the domain and subdomain
14 level.

15 Next slide. So, we did find that
16 there were, in general --- there was, in general,
17 a high degree of agreement among the groups, but
18 there were some areas where stakeholder groups
19 differed with respect to how important they
20 thought these outcome areas were to measure.

21 And that's important to understand
22 that they were basically working off the NQF

1 framework and the operational definitions that
2 each of those areas provided and were really
3 providing weightings of measurement importance
4 rather than how important are these domains to
5 them personally.

6 The areas where we found some
7 significant effects were in choice and control,
8 consumer leadership in system development, human
9 and legal rights, community inclusion, and
10 service delivery and effectiveness.

11 Next slide. I'm going to just go
12 through the next several slides pretty quickly to
13 just give you kind of an overview of some of the
14 things that we found. And many of these
15 differences are things that, you know, we really
16 expected to find.

17 So, for example, you know, we found
18 that, you know, across the groups, the group of
19 family members -- or the groups of family members
20 tended to weight personal choice and control
21 significantly lower in importance than both
22 providers and individuals with disabilities.

1 Next slide. You know what? Go ahead.

2 Next. We'll go one more. At the subdomain
3 level, we found some interesting differences in
4 that persons with age-related disabilities rated
5 personal choice as significantly more important
6 to measure than the other disability groups.

7 And, again, these are based upon Z-
8 scores. So, we're taking a look at kind of the
9 average importance weightings that people
10 assigned across the domains and subdomains, and
11 then the extent to which their weightings and
12 specific areas were significantly above and below
13 that.

14 Next slide. Still staying within the
15 domain of choice and control, you can see that
16 when we discuss self-direction of persons with
17 physical disabilities, so within that group,
18 there was an interaction between the stakeholder
19 group and the disability types. Persons with
20 physical disabilities rated self-direction as
21 relatively important.

22 Next slide. Providers for the IDD

1 group rated self-direction as below average
2 importance to measure. And, again, this is
3 directing your own -- excuse me -- directing your
4 own service planning and service delivery.

5 Families of individuals with
6 disabilities, on the other hand, rated self-
7 direction as of average importance.

8 Next slide. In human and legal
9 rights, you can see, as expected, you know, all
10 groups rated them as important. But individuals
11 with disabilities rated that area as
12 significantly more important than provider
13 members and family.

14 Next. The highlighted areas are just
15 the areas that we're going to focus on. So, if
16 we can go to the next slide, okay, you can see
17 that, again, there were some differences in
18 providers rating the optimization of legal and
19 human rights as significantly less important than
20 family members.

21 Next. Persons with IDD rated
22 community inclusion as significantly more

1 important to measure than all of the other
2 groups.

3 Next. Next slide. And the subdomain
4 of meaningful activity was rated significantly
5 more important by persons with physical
6 disabilities and intellectual and developmental
7 disabilities compared to the aging population.

8 Again, just to remind the group that
9 we're talking about how important people felt
10 these were to include in measurement systems.

11 Next slide. So, in addition to
12 collecting quantitative data, we also got a lot
13 of input from individuals which we have partially
14 analyzed, we certainly are not finished with that
15 yet, that took a look at whether there were new
16 domains or subdomains that the groups thought
17 needed to be added to the NQF framework.

18 And we found that, you know, in the
19 areas of community inclusion, choice and control,
20 system performance and accountability, and
21 holistic health and functioning, we had a number
22 of groups -- and those numbers reflect the number

1 of groups that suggested additional domains or
2 subdomains among all of those groups that we --
3 that we had derived.

4 Next slide. Okay. So, again, I'm
5 just giving you some quick examples.
6 Recommendations for the domain of community
7 inclusion included, you know, the need to ensure
8 that measurement developers are focusing to a
9 greater extent on diversity and cultural
10 sensitivity, community outreach and education,
11 and individuals with disabilities feeling
12 welcomed and valued.

13 This is an area that we spent a lot of
14 time discussing with our group who had very
15 strong feelings about how community inclusion is
16 currently measured in the most widely used
17 measurement frameworks where it tends to be more
18 focused on how often individuals get out into the
19 community rather than their experiences within
20 the community.

21 What we heard again and again from
22 groups is, we really should be doing a better job

1 focusing people being of the community than
2 rather just being physically in it.

3 Next slide. Recommendations for
4 choice and control indicated the need for
5 individuals with disabilities to be more
6 effectively supported and empowered and to have
7 more choices available to them.

8 The group felt that the current
9 framework really didn't place enough emphasis in
10 either of these areas.

11 Next. This area was an area that we,
12 when we originally focused on the NQF framework
13 ourselves, thought was missing. And we were
14 interested in seeing across the stakeholder
15 groups, what groups felt that employment needed
16 to be more attended to than it currently is.

17 Currently, as you know, in the domain
18 of community inclusion, there is a subdomain
19 called Meaningful Community Activity. And within
20 that is employment.

21 We heard from a number of our groups,
22 specifically persons with disabilities, family

1 members and providers, of the need for the
2 framework to include employment as a separate
3 domain, because they really had concerns that it
4 would not be effectively addressed by measure
5 developers if it did not have inclusion at that
6 level.

7 Next slide. So, that just gives you
8 a quick overview of some of the things that we
9 learned in our Study No. 1.

10 I think, you know, the major take-
11 aways is that the work group that developed the
12 HCBS NQF measurement framework did a good job in
13 hitting on most of those areas.

14 We have a lot of information from our
15 various stakeholder groups about how each of
16 those subdomains might be further improved and we
17 are in the process of putting together a
18 technical report that we will share with everyone
19 that will lay out in much more specific form, you
20 know, each of those recommendations.

21 So, that study was a study that really
22 needed to take place, we felt, before the

1 development of our measures.

2 As in Study No. 2, which my colleague,
3 Renata Ticha, will share with you, which is the
4 gap analysis, taking a look at the NQF framework
5 and its existing domains and subdomains, and
6 existing instruments and measures that are being
7 used to take a look at HCBS outcomes.

8 Renata.

9 DR. TICHA: Yes. So, Study 2 is
10 basically an effort that started about a year
11 ago. And we have a team of us, about five of us,
12 working on that study.

13 And we are reviewing and cataloging
14 all the instruments that we can find across the
15 disability areas that already exist and mapping
16 their areas or subscales and their items onto the
17 NQF framework as our first step.

18 Next slide. So, some of the main
19 questions for the Study 2, is the extent to which
20 the measures are mapping onto the NQF framework
21 and looking at the different characteristics of
22 those instruments, which is -- and I'm looking at

1 the following slide right now.

2 So, some of the characteristics
3 include response options, respondent type, type
4 of data, whether the items within the instrument
5 are person-centered, and if the instruments have
6 psychometric qualities, including reliability and
7 validity.

8 So, we can look at the next slide.
9 Some of the instruments that you can see there,
10 these are just, really, examples, because we are
11 close to coding a hundred instruments at this
12 point, but you can see some of the really big
13 ones that include National Core Indicators and
14 the different types of surveys under that
15 program, as well as some of the other ones that
16 you can see that are big.

17 One of the one's that's a little
18 different that you can see, number 19 is the
19 PEONIES assessment developed in Wisconsin.

20 So, as you can see, we have a variety
21 and different types of assessments that we have
22 coded so far.

1 We can look at the next slide. How
2 has -- the method that we have used apart from
3 just cataloging the 95, and now it's about a
4 hundred, instruments, is really code every single
5 item within each of the instruments that has
6 mapped onto the NQF framework.

7 So, we are in the 5,000s of coding the
8 different items across the different
9 characteristics that we have just gone over. And
10 a lot of them have been assigned to the different
11 codes that we are coding. Some of them that have
12 not been assigned are just demographic questions
13 or questions that don't directly map onto the NQF
14 framework.

15 Next slide. This slide, in detail,
16 lists the different variables that we have coded
17 each of the items within each of the instruments.

18 So, apart from the NQF domains is
19 subdomains. You can see I was mentioning the
20 person-centeredness, the target population, the
21 purpose, psychometrics and also coverage area.
22 So, we are looking at very primarily those

1 instruments are being used.

2 Next slide. So far, we have learned
3 that of course there are some items in some
4 instruments that are, more or less, covering the
5 NQF framework. And I will show you some numbers
6 in the following tables.

7 We have learned that a lot of the
8 subdomains overlap. So, we end up double or
9 sometimes triple coding some of the questions
10 within instruments.

11 We are also learning that there are
12 less questions or items that cover the systems-
13 level performance and accountability versus the
14 individual -- more individual-level domains and
15 subdomains.

16 We have fewer items covering the
17 caregiver and caregiver support subdomains. And
18 also, not many items are covering consumer
19 leadership and system development. So, those are
20 some of the broader areas of coverage by the NQF
21 framework.

22 If you look at the next slide, this is

1 information -- we are currently developing a
2 database of these measures as they map onto the
3 NQF framework.

4 And the purpose of the database really
5 will be for people to be able to see what
6 measures that already exist, but also the ones
7 that will be developing and refining, how do they
8 map onto the NQF framework as they exist, but
9 also how it's being refined by the results of
10 Study 1 that Brian has gone over.

11 I'll show you on the next slide an
12 example of a dashboard that is kind of a
13 precursor of the database that we are working on.

14 So, you can see in the table on the
15 left-hand side, the coded items by domain. And
16 so, you can see how many codes are for community
17 inclusion, for example, for choice and control in
18 relation to some of the ones that I highlighted
19 that have not been covered as well that goes to
20 equity, consumer leadership, and system
21 performance and accountability.

22 And on the pie chart on the right-hand

1 side, you can see the percentage of coverage
2 rather than just the raw numbers that you have in
3 the table.

4 Moving on to the next slide, the next
5 slide that's titled Instrument Heat Map, conveys
6 similar type of information, but in a slightly
7 different format.

8 So, you can see on the x-axis, you
9 have the names of the instruments, the National
10 Core Indicators, PEONIES and so on. And then on
11 the left-hand side on the y-axis, you have the
12 domains. And then you can see kind of the level
13 of coverage of the NQF domains within each of the
14 instruments. So, that's also available on our
15 dashboard.

16 DR. ABERY: And then one thing which
17 we aren't able to show you just because of size,
18 is the fact that one can also look at that across
19 each of the subdomains.

20 So, in some areas where there appear
21 to be a lot of -- some domains where there appear
22 to be a lot of questions, you know, those

1 questions really aren't equally distributed
2 across the subdomains. So, we may have many
3 measures that focus on only one subdomain within
4 a domain rather than adequately covering all of
5 the subdomains.

6 DR. TICHA: Yes. So, on the next
7 slide, that's really an interesting slide,
8 because it does combine the data from Study 2
9 that Brian was describing, the groups, the PPDM
10 groups, and also from the gap analysis.

11 So, you can see the coverage of items
12 of the different domains, but also you can see
13 how the groups across the country have rated them
14 in importance and if there are any similarities
15 and differences.

16 MEMBER POTTER: Hi. Could you give us
17 a quick walk-through of how to interpret the
18 colors on this, please.

19 DR. TICHA: Yes, absolutely. So, the
20 darker the green color, the better coverage of
21 items of the different domains.

22 So, for example, if you look at the

1 domain of community inclusion, we have not -- we
2 have coded 972 items that in some way cover the
3 domain of community inclusion.

4 It doesn't speak to the quality of the
5 questions, but this is just a quantitative
6 coverage.

7 In the same way in the same line,
8 there is about 92 percent of the way that people
9 saw this domain as important. So, it's not as
10 important as, for example, choice and control,
11 but choice and control only has about 620 items
12 that cover -- which is still very large -- of
13 that particular domain.

14 Does that help?

15 MEMBER POTTER: Yes. Thank you.

16 DR. TICHA: Okay.

17 CO-CHAIR MONSON: So, I had just a
18 question around the instruments. So, you said
19 there was like 94 instruments, but you've listed
20 a bunch of them, all very good ones.

21 I didn't see any on there that were
22 state-based assessments like the 701 B from

1 Florida or the NRI, which is utilized.

2 So, are those included as well and
3 they just didn't make it onto these charts?

4 DR. TICHA: Yes. So, that's a really
5 good point. We have included a number of the
6 state-level assessments. And we would be very
7 happy to share with you the, you know, the whole
8 dashboard with all of the assessments.

9 But as you say, only the ones that
10 have really large coverage are -- we coded --
11 some of the first ones were included on that
12 particular slide.

13 MEMBER ROSS: Hi. I have a question.
14 This is Clarke Ross with the Consortium for
15 Citizens with Disabilities. Two questions.
16 These are instruments currently coded.

17 When I joined this National Quality
18 Forum group in 2012, I asked for an analysis of
19 PEONIES and was told that only two counties in
20 Wisconsin currently use it and that it didn't
21 meet a meaningful threshold of implementation
22 even though the domains were wonderful.

1 So, this is my first question of two:
2 is -- do you have a threshold on use, and has
3 PEONIES increased its utilization of
4 implementation?

5 DR. ABERY: Okay. We did not have a
6 specific threshold of use. One of the things
7 that we wanted to do is to include instruments
8 which were new.

9 We were also encouraged by our NIDILRR
10 project officer and the individuals who we've met
11 within ACL, to include instruments that had been
12 developed in this area specifically for, for
13 example, federally-funded research projects which
14 while they might not be widely used, in some
15 cases are the instruments who have the best
16 psychometric data available on them to attest
17 their reliability and validity.

18 We did include PEONIES within our
19 analysis and have met with its developer, Sara
20 Karon, on a number of occasions.

21 What has happened in Wisconsin, is
22 that PEONIES has morphed into a similar type of

1 instrument which is referred to as -- Renata, do
2 you remember?

3 DR. TICHA: IRIS.

4 DR. ABERY: IRIS. You know, so that
5 it is still being used in a sense; however, it is
6 not being used as far as we have been able to
7 track down outside of the state of Wisconsin.
8 Although, it does include, we think, some very
9 unique ways of taking a look at HCBS outcomes
10 which are significantly more person-centered than
11 some of the other instruments that -- many of the
12 other instruments that we've reviewed.

13 MEMBER ROSS: So, I agree on the value
14 and importance, but -- that's why I suggested it
15 years ago.

16 But when you think about health plans
17 and payers, something that's academically
18 developed that's only been used in a couple
19 counties and is no longer currently used is not
20 really relevant.

21 It's a helpful academic conceptual
22 thing, but it's -- the implementation experience

1 is important.

2 And then my second question, I don't
3 see the council and quality and leadership
4 personal outcome measures on the currently-coded
5 instruments. Do you plan to analyze that?

6 DR. TICHA: Actually, that's -- that
7 has already been coded and analyzed. That's one
8 of our main instruments that we have dealt with.

9 MEMBER ROSS: Thank you.

10 DR. TICHA: Yes. I just wanted to
11 also add to Brian's response to the PEONIES.

12 So, we -- as we have completed -- or
13 are completing Study 1 and are learning from the
14 quantitative, but also the qualitative
15 information what the stakeholders are seeing as
16 critical areas, one of the things that has come
17 up, for example, under community inclusion, is a
18 social inclusion that wasn't included as a
19 specific subdomain of the particular domain.

20 And instruments like PEONIES really
21 have the capacity to address some of the more
22 softer subdomains that are not as easily

1 measured with some of the hard-core quantitative
2 instruments. So, that's why we are still keen to
3 include that instrument in our work as we move
4 forward through the Center.

5 DR. ABERY: Okay. If there are no
6 other questions, our next slide, please -- oh,
7 and I should say before --

8 MEMBER ROSS: Well, this is Clarke
9 again. I just -- PEONIES is a wonderful
10 instrument. That's why I advocated it years ago
11 here.

12 But if it's not used as an advocate,
13 it's hard for me to convince the health plan
14 folks around the table, and others -- I mean,
15 it's a nice resource. It's well thought out. It
16 has great domains.

17 You said it had good definitional
18 properties, but -- that's my frustration is --
19 and I work closely with Joe Caldwell and I'll
20 talk to him about this, but how much attention do
21 we give to something that's not implemented
22 almost anywhere.

1 DR. TICHA: Right. And, you know, so
2 maybe we should go back to the beginning of our
3 presentation a little bit.

4 So, the purpose of our center is not
5 to promote, you know, some instruments over
6 others or say -- sort of recommend an instrument
7 over others, but it's really to pull items or
8 measure concepts and measures eventually when we
9 get there, that will be based on these
10 instruments.

11 So, for example, if we are suggesting
12 to measure social inclusion or we are suggesting
13 to measure choice and control or decision-making,
14 we are going to be recommending measures that
15 will be sets of items that we are basing on these
16 existing instruments and then filling gaps and
17 refining them to recommend those.

18 So, I hope people understand what our
19 mission is that it's not just recommend an
20 instrument, it's recommending measures at the end
21 of our cycle.

22 CO-CHAIR MONSON: So, this is Michael

1 Monson from Centene again. I think I understood
2 all of that.

3 I think it's really important, though,
4 that as you do that, you do that in the context
5 that, first of all, some are proprietary
6 instruments, some are not.

7 So, if you're going to take specific
8 questions, for instance, from instrument A and
9 say that that's the right question to get to,
10 let's say, a choice and control measure, but
11 instrument A is a proprietary measure and then
12 you're taking question 3 from instrument B that's
13 also a proprietary measure that gets you to
14 another measure, we could end up with kind of a
15 mash-up of different questions from different
16 instruments and it will be extraordinarily
17 difficult to implement.

18 So, I guess I would encourage you to
19 think about how you use -- because where you end
20 up will direct us back to what we end up doing in
21 the real world.

22 And I think we look -- I know that

1 from a health plan perspective, we would be
2 thrilled to have one standard assessment across
3 all states for managed long-term services and
4 supports, assuming it's a good assessment, you
5 know, and assuming that we can always add
6 additional questions to it.

7 But what would be really difficult
8 would be that we end up with states saying, well,
9 we want to measure this. And, therefore, you
10 need to go buy this question from NRI and this
11 question from PEONIES and this question from over
12 here and having resistance from them because they
13 won't parse it out that way.

14 So, I just -- I don't think you can --
15 I just would really encourage you to think about
16 the end point as much as the journey you're on
17 right now, because it needs to be something
18 that's actionable for all of us so that we can
19 actually get to where we all want to get to with
20 some standard measures that we can all use to
21 improve the system.

22 DR. TICHA: Yes. And thank you for

1 the question. It's a real important one. We are
2 kind of in the thick of figuring that out right
3 now, the proprietary material versus the one that
4 is not. Also, versus -- we are looking at the
5 questions that are covering certain measure
6 concepts right now. And some of them are great,
7 but some of them are not so good.

8 And so, we are really refining and
9 developing additional questions for each of the -
10 - each of the domains and subdomains -- well, not
11 each, but the ones we are focusing on.

12 And the other piece of this is that we
13 really have to pay attention to if -- when we
14 were showing you some of the dashboard diagrams
15 and some of the heat maps, if the domain or
16 subdomain really doesn't have sufficient coverage
17 and it doesn't have questions that a gap -- like
18 Brian was giving the example of community
19 inclusion domain didn't really capture what
20 people are telling us in our groups, which is the
21 engagement -- the active engagement of the person
22 with a disability in the community.

1 So, we'll have to come up with
2 questions that are not really included in any
3 other instrument that, you know, be it -- I don't
4 want to name specific instruments, but be it some
5 of the ones that are the big program of
6 assessment for the disability populations.

7 And so, we are really kind of in the
8 thick of thinking this through and we certainly
9 take your point into consideration very
10 seriously.

11 CO-CHAIR MONSON: So, the only other
12 thing I would add to that would be -- and I
13 appreciate you taking it into consideration.

14 The only thing I'd add is as you think
15 about adding questions, remember that when these
16 assessments are conducted, they're already 90 to
17 120 minutes, sometimes longer, which is a burden
18 on all participants.

19 And so, I know one of the NQF
20 principles is parsimony. So, just bear that in
21 mind, I guess I would ask you, about what's
22 really important, right.

1 And, I don't know, maybe at the end of
2 this you are going to have a ranked order of
3 questions and some new standard assessment that
4 you're proposing, which would be great assuming
5 it's one that is not proprietary.

6 But just bear in mind the burden level
7 that comes from a family caregiver or a
8 participant having to participate in that. And
9 it's a long -- it's a long session.

10 And then, also, obviously the cost
11 that comes with that from either the fee-for-
12 service side or the managed care side.

13 DR. ABERY: Those are all excellent
14 points. One of the things that we probably
15 should have indicated more clearly is we are
16 working quite closely with the major measurement
17 development programs, several of them, as part of
18 this process.

19 We see ourselves, you know, not
20 developing these -- any additional measures or
21 refining measures in isolation, but rather
22 working with those groups to help improve those

1 measures.

2 I mean, we do not intend to produce
3 the instrument, that was not the intent of our
4 Center, but to improve measurement quality among
5 all those groups that are, you know, currently
6 using instruments which are widely used across
7 the country.

8 MEMBER POTTER: Hi. This is D.E.B.
9 Potter from ASPE. I guess I was a little
10 confused by your last statement of not developing
11 the instrument.

12 Because when I looked at one of your
13 first slides, you say eventual objective is NQF
14 endorsement. And the only way you can get NQF
15 endorsement is, quote, to have an instrument.

16 DR. ABERY: Well, actually --

17 MEMBER POTTER: So, maybe you could
18 expand that a little bit.

19 DR. ABERY: We will not be -- we will
20 not be asking for NQF endorsement of an
21 instrument.

22 We will be asking for NQF endorsement

1 of measures that correspond to the NQF subdomains
2 in most cases, as opposed to attempting to
3 develop an instrument such as the NCI, which
4 covers multiple domains and multiple subdomains.

5 Our goal is to improve measures. And
6 once those -- that measurement testing is done,
7 you know, we do not see the measure that we
8 developed there as proprietary. We are more than
9 willing to share them with all of the measurement
10 organizations that are currently being used by
11 states.

12 So, I think we're basically
13 differentiating between an instrument and
14 measures that together would comprise an
15 instrument.

16 MEMBER POTTER: I guess I would urge
17 you to read the updated NQF requirements for
18 person-reported outcome measures and then consult
19 with the NQF staff on how that would happen given
20 the current endorsement process for person-
21 reported outcomes, which is what you're talking
22 about.

1 MS. MUKHERJEE: And, D.E.B. and Brian,
2 I can give a quick sort of update on that. So,
3 NQF does not endorse a tool or a survey.

4 What they are doing is endorsing
5 patient-reported outcome measures based on
6 elements within the survey and within the tool.

7 So, in the past, when surveys first
8 came out, NQF did endorse a survey as a measure,
9 but right now because the field has evolved and
10 moved on, if it's a survey or a tool, we do not
11 endorse it as a measure.

12 What we will do is ask for the
13 development of patient-reported outcome measures,
14 which is taking elements of the tool or the
15 survey and creating performance measures.

16 DR. TICHA: Yes. Thank you. And
17 that's exactly what we are doing. And we do have
18 a number of the members of the NQF committee on
19 RRTC. So, we consult them on a monthly basis.
20 So, but -- yeah, thank you for that point.

21 MEMBER ROSS: This is Clarke Ross, if
22 I could ask one other question. You say you've

1 been closely consulting with some of the
2 measurement organizations, I assume National
3 Quality Forum and Council on Quality and
4 Leadership on personal outcome measures.

5 They've been reluctant to submit
6 anything to the National Quality Forum, because
7 their philosophy is you cannot pull out one
8 measure from the mosaic of domains that they
9 capture.

10 So, as an advocate, it would be
11 helpful to pull out one measure and have it
12 endorsed, but it runs counter to the philosophy
13 of both NCI and CQL.

14 And so, I'm just trying to get my
15 handle on the utility of your federally-funded
16 project with all the experts saying, "Yeah, we'd
17 like these four measures of 22 endorsed because
18 of their importance and validity and all that
19 stuff."

20 And so, I'm -- it's more a question --
21 I'm just trying to sort this out in my own mind
22 on the utility of recommending unique measures

1 that the developer themselves say need to be
2 viewed in the total context of what they're
3 trying to do.

4 DR. TICHA: Right. And, you know, I
5 think we really appreciate that question and
6 that's a question we have been thinking about
7 from the time we wrote the proposal.

8 And I think, you know, Brian already
9 indicated that we work very, very closely with
10 the developers of the major assessment programs.

11 And, really, we see our charge as
12 looking at not necessarily the domains/subdomains
13 in isolation. But if we look at the psychometric
14 properties of some of these measure concepts,
15 they essentially have to be looked at in
16 isolation to the point that they constitute a
17 unique and differentiated concept or construct.

18 So, we have to confidently -- we have
19 to be able to measure, for example, you know,
20 social inclusion or choice and decision-making as
21 its own entity regardless of how it relates to
22 the others, for example, using factor analysis or

1 using other statistical techniques.

2 So, I think they are not mutually
3 exclusive and we just -- our charge, really, is
4 to find the best possible questions to measure a
5 measure concept or a construct across different
6 instruments not to say that one is better than
7 the other, it's just how do we conceptualize a
8 measure concept in the best way possible.

9 CO-CHAIR MONSON: Yes. Go ahead.

10 MEMBER POTTER: Hi. This is D.E.B.
11 Potter again. Additional clarification.

12 So, in the end, you might say -- this
13 is just an example -- questions 3, 4 and 5 from
14 survey A are the best way to measure community
15 inclusion, but will you also say these other ways
16 are valid?

17 I'm sort of back to the operational if
18 we're going to measure community inclusion from
19 survey A and we're going to measure employment
20 from survey B and we're going to measure X from
21 survey C, no one organization can administer all
22 of those and how do you get it down to something

1 that's operational without overburden, or am I
2 not understanding your goal?

3 DR. TICHA: So, I think -- I think the
4 way you're asking the question, you are
5 understanding the goal well and I think there are
6 two pieces to this question.

7 One is when we conceptualize a
8 measure, it's essentially a theoretical concept
9 or a theoretical construct such as social
10 inclusion, choice and decision-making, and the
11 questions that get asked are really secondary,
12 right?

13 They are really -- the goal of asking
14 the best possible questions is to be able to
15 saturate a construct to ask the question in such
16 a way that they are valid, that they really get
17 at that subdomain or that measure concept.

18 And we can only determine that after
19 we have conducted really sound, statistical
20 analysis that include internal consistency,
21 factor analyses and other analyses that
22 differentiate a measure concept and --

1 MEMBER POTTER: I buy all of that, but
2 where is question order effect in here?

3 DR. TICHA: Where is what again?
4 Sorry.

5 MEMBER POTTER: Question order effect,
6 i.e., in this survey, the questions are question
7 10, 11, 12, and in this survey, they're questions
8 24, 25 and 26.

9 DR. TICHA: The --

10 MEMBER POTTER: Question order effect
11 is a well-known survey research construct that
12 affects the validity and reliability of whatever
13 you're trying to measure.

14 DR. TICHA: Yes. You know, at this
15 point, we are just working with our data from
16 Study 1, really, and then the information from
17 Study 2.

18 Our next step is to -- we are about 10
19 days or two weeks away from identifying our
20 measure concepts that we'll be piloting.

21 Once we have the measure concept
22 identified, we are going to look at the, you

1 know, 6,000 questions we have coded for across
2 the hundred instruments. And we are going to map
3 those onto those measure concepts.

4 And then once we have those, we are
5 going to contact the developers of the
6 instruments that these questions are potentially
7 coming from, or the questions we are going to
8 develop if they are missing. And then that's
9 going to be our next step in taking it into the
10 piloting stage.

11 So, we already are in very close
12 contact with the programs that might have some
13 other really good questions.

14 CO-CHAIR MONSON: So, you guys -- you
15 all on the phone can't see us, I know, but you're
16 seeing a lot of kind of furrowed brows not
17 because -- everyone is really interested in this
18 and very concerned that you get it right, right,
19 because this is a really important endeavor. So,
20 I think there are people in this room who
21 probably have a lot of value to add.

22 And one thing I encourage you is to

1 maybe have another forum, because this is --
2 we're going to run out of time soon where, you
3 know, people -- the experts in this room
4 potentially who want to participate can provide
5 you some more insight.

6 DR. TICHA: And we really value the
7 feedback because, you know, we have a certain
8 approach to this, the way we have written the
9 grant.

10 We do have an advisory board that some
11 of you -- actually, some of the people who ask
12 questions are on our advisory board, but we would
13 love to get as much feedback as possible
14 especially at this critical stage when we are
15 selecting our measure concepts for piloting.

16 DR. ABERY: Keep in mind that those
17 first two studies really were to orient us to
18 what is viewed by stakeholders as most important
19 to measure, and what are the things that are not
20 being measured right now.

21 There is a lot of measurement taking
22 place which has little psychometrics to back it

1 up at this point, you know. There are constructs
2 that we say we're measuring and they would appear
3 to the typical person to be measures where the
4 necessary research and analysis has not been done
5 to demonstrate that they are valid and that they
6 are reliable.

7 And some of those are included in some
8 of the most frequently used measures both
9 nationally and within our own state of Minnesota.

10 CO-CHAIR MONSON: So, the one last
11 thing I would say on this, the conversation
12 heretofore has been really focused on patient-
13 reported outcomes, which is hugely important, but
14 those are not the only outcomes.

15 To hit all those domains, there are
16 other measures and instruments that you'll need
17 beyond patient-reported outcomes; claims-based
18 data, observational data.

19 And so, I guess I would just encourage
20 you all to think about the measure developers
21 that you're working with are great measure
22 developers for patient-reported outcomes, at

1 least the ones you've mentioned like NCI, right?

2 They're fantastic, but they may not be
3 the ones that are helpful in figuring out how do
4 we best, you know, figure out the transitions for
5 a nursing facility, net transition number, or how
6 do we think about functional improvement for
7 individuals who are receiving these services.

8 So, I would just leave that with you
9 as well.

10 DR. TICHA: Yes. Yes. Thank you.
11 And we would encourage all of you to, please, get
12 in touch with us with any comments or
13 suggestions.

14 We are also open to doing another
15 forum like this. We have compiled a -- more of
16 an interactive framework for feedback for the
17 stage that we are at.

18 So, we would be -- our colleagues who
19 work with us as project coordinators would be
20 happy to schedule something like this to go into
21 more depth. So, thank you again.

22 CO-CHAIR MONSON: Great. Was there

1 more that you guys -- we've kind of hijacked the
2 conversation, but was there more material that
3 you wanted to cover?

4 DR. ABERY: Well, there was quite a
5 bit more material, but we don't realize how much
6 time you have.

7 So, if you could kind of direct us as
8 to how much additional time we might have, we can
9 quickly go through kind of the meat of the RRTC's
10 proposed work over the next four years or so.

11 CO-CHAIR MONSON: We've probably got
12 another 20-25 minutes that we can keep going.

13 DR. ABERY: Okay. So, we can probably
14 give you a pretty quick summary of what we are
15 planning to do in Studies 3, 4, 5 and 6.

16 Study 3 is just starting. Study 4 and
17 5 will be starting with -- Study 4 in the next
18 few months.

19 So, Study 3 basically is focusing --
20 if we can have movement to the next slide -- on
21 identifying existing outcome measurement programs
22 in which NQF-related HCBS outcome measures are

1 being implemented and then to conduct a series of
2 case studies to take a look at the quality of
3 those measurement approaches and programs.

4 So, essentially, the idea behind this
5 study is to take a look at the fidelity of
6 administration and implementation of these
7 measurement programs via the major
8 players/organizations that are doing HCBS outcome
9 measurement across the states.

10 Next slide. And essentially what
11 we're going to be hoping to identify are the
12 components that need to be in place to ensure
13 that there's a high degree of administration
14 fidelity, we're going to be identifying the
15 strengths and challenges of the various
16 approaches that measurement programs are
17 currently taking, similarities and differences,
18 and really looking at the factors that either
19 facilitate or serve as barriers to effective
20 implementation of the programs.

21 So, this is a qualitative study. Our
22 only real qualitative study of the Research and

1 Training Center is being PI'd by Dr. Amy Hewitt
2 from our center. And that is a study which is
3 starting within the next few weeks with some work
4 with the people from CQL.

5 So, we'll be looking at
6 instrumentation, sample and recruitment, you
7 know, across a number of different sites.

8 Study 4, and if we can move ahead with
9 a couple of the slides and get to Study 4, is
10 where after we select, based upon the gap
11 analysis, those areas in which we feel that there
12 is the greatest need for further measure
13 development.

14 We will be working with several
15 technical expert panels and with our colleagues
16 from Temple University, UCSF, and The Ohio State
17 University to either refine existing measures or
18 to develop new measures and then to go through a
19 development and testing process using the CMS
20 criteria as we go through the process.

21 And I think there are a couple of
22 slides which just look at the measure life cycle

1 which had been incorporated into the process that
2 we will be using.

3 So, if we can move ahead to Slide 56,
4 which focuses on measure evaluation criteria, we
5 will be looking at all of these in selecting the
6 measures that we will be working to either newly
7 develop or refine focusing on importance,
8 feasibility, usability, harmonization, and of
9 course scientific acceptability.

10 So, if you look at the next slide,
11 that really is the focus of kind of the pilot
12 study which is done in Study 4 which will be
13 looking at inter-rater, test-retest and internal
14 consistency, reliability and a number of aspects
15 of validity.

16 Next slide, please. As part of this
17 iterative process, we will be, again,
18 prioritizing measures to develop based upon the
19 combination of stakeholder input from Study 1.

20 Those areas that currently are not
21 being measured or not being measured well where
22 there isn't adequate saturation of the concepts

1 will be our focus.

2 We will then be bringing together both
3 among our research team members and technical
4 expert panels, a group of individuals to work on
5 this.

6 We are addressing the need for proxy
7 reports and minimizing the burden to the
8 individuals who we are requesting information
9 from.

10 And then, again, we'll be looking at
11 going through a process where we have kind of
12 expert content review, cognitive testing and
13 doing a relatively small, n=100 pilot study.

14 One of the things that we are really
15 keen to do is the cognitive testing to ensure
16 that since we are trying to develop measures that
17 cut across groups, that the different groups are
18 interpreting the questions that we are asking in
19 order to get information, collect data so that we
20 can have measures, or actually interpreting the
21 questions in the same manner and in the manner
22 that we intend.

1 That piece has really been absent from
2 a lot of the work that has been done in this
3 area.

4 Again, the next slide, if we move on
5 to it, just gives you kind of an indication of
6 what we'll be doing in the pilot study,
7 identifying issues or concerns with
8 administration and scoring, determining the
9 acceptability of measures and the acceptability
10 of measures to the recipients, obtain feedback on
11 the response formats and wordings, and then
12 determining the extent to which there's
13 variability within -- between items and within
14 measures.

15 Renata, you want to talk quickly about
16 Study 5, which is our large-scale study?

17 DR. TICHA: Yeah. So, Study 5 is just
18 the logical progression in this whole process
19 toward NQF endorsement.

20 After in Study 4, we have piloted some
21 of the really promising measure concepts based on
22 the NQF framework. We will then work with those

1 measure concepts a little bit more to refine
2 them, to add some, perhaps.

3 And then in Study 5, it's our large-
4 scale study, hopefully a national study, that we
5 will then test those concepts on a thousand
6 participants across all of the different
7 visibility groups.

8 And so, we are currently in the
9 process of recruiting sites. So, if there are
10 any interested sites across the country who would
11 like to work with us in the testing study that
12 will start in about a year, we would very much be
13 interested in that and will be looking at those
14 psychometric properties that are listed on the
15 slide; reliability, validity, item
16 discrimination, sensitivity to change, but we
17 will also cover some of the more basic criteria
18 for feasibility, usability, importance and all of
19 the CMS criteria that they have.

20 And we already will of course be
21 working with some of the big programs like NCI,
22 CQL, but we would love to work with any sites

1 that are interested for that big study.

2 The data collection from Study 5 will
3 be longitudinal to look at some of the
4 sensitivity to change of some of those concepts
5 and would like, as I said, would like to
6 collaborate. And we do have some funds built
7 into the grants for the collaboration.

8 And just briefly and in the rest of
9 the time that we have, Study 6 is already
10 underway. It is a study that has been reviewing
11 different risk adjuster variables from studies
12 across the different populations, identifying the
13 most promising risk adjusters across the NQF
14 outcomes.

15 And we will be including some of the
16 risk adjusters that we have identified over the
17 last six months or so into the pilot study, but
18 also into Study 5 to test alongside the measures
19 of the outcome so we can look at potentially also
20 at some of the relationships.

21 And, again, if you have any ideas or
22 any input into risk adjusters, we would be happy

1 to share more detail about the study. We are
2 currently working on a manuscript of the Study 6
3 results. So, that's where we are with that.

4 And let me just -- I'm sorry, I'm
5 skipping a little bit here, but on one of the
6 slide that's titled "Coding Progress," you can
7 see that as of about ten days ago, we have been
8 able to code almost a thousand different
9 variables from about 60 studies. And you can see
10 the breakdown by systems and by individual
11 levels.

12 And of those, we have identified about
13 42 promising risk adjusters that will be then
14 narrowing down for the testing phases.

15 And on the following slide, there are
16 some examples of the categories of risk adjusters
17 that cover functional disability, chronic
18 conditions and risky behavior. So, those are the
19 ones that are appearing more frequently.

20 MEMBER ROSS: Excuse me. This is
21 Clarke Ross again. So, a lot of folks in the
22 health policy arena and the National Quality

1 Forum have been trying to get away from a
2 diagnosis as a risk category, because, you know,
3 there are hundreds of chronic illnesses that are
4 debilitating -- potentially debilitating.

5 So, how are you building diabetes,
6 cancer and epilepsy and all the forms of cancer
7 as a risk adjuster?

8 DR. TICHA: Yeah. So, maybe I should
9 just give a little bit of a context. So, this
10 initial stage of our Study 6 on risk adjusters
11 has been very broad.

12 We have cast a very, very broad net to
13 really provide interested audiences with what has
14 been done so far in the field of risk adjusters
15 with these populations.

16 So, some of the ones we have got on
17 the slide here that you are referring to, are
18 just to say that they have been studied and
19 included in the past, but it's not necessarily
20 something they'll be considering to include in
21 relation to the NQF framework.

22 CO-CHAIR MONSON: So, this is Michael

1 Monson. Again, I would just say, also, on the
2 functional disability, that is going to be very
3 dependent on having a standard set of
4 observational questions.

5 DR. TICHA: Uh-huh.

6 CO-CHAIR MONSON: I would encourage
7 you to look at the work that's happened in New
8 York and Wisconsin around functional-based risk
9 assessment for rate setting on the managed LTSS
10 side, because they've actually done a lot of good
11 work there.

12 DR. TICHA: Uh-huh.

13 CO-CHAIR MONSON: But it is going to
14 -- that -- if you're going to use that -- and it
15 should be used as a risk adjuster, but it will
16 require us to have standard elements across every
17 assessment to be able to do that.

18 DR. TICHA: Yeah. You're absolutely
19 correct. And if you have a specific reference
20 that we should look at, please share it with us.

21 CO-CHAIR MONSON: The -- we will.

22 DR. TICHA: Okay. Thank you.

1 Yeah. So, again, so these -- the ones
2 that we put on the slide are just some of the
3 ones we have seen as reoccurring across the
4 studies that we have reviewed. And that goes
5 back to the current take-aways.

6 We did find that most of the risk
7 adjusters across the studies were not well-
8 matched to the HCBS outcomes. And there's a
9 strong tendency to focus on the personal
10 characteristics of the recipients. And there are
11 many newer risk adjusters that have been studied
12 well that are at a systems and the organizational
13 level.

14 And so, we'll be making a big effort
15 to get input from our -- from stakeholders from
16 our advisory board and our leadership team on
17 which variables to actually include in our pilot
18 in our big study for risk adjustment.

19 So, our next steps will be to
20 prioritize risk adjusters in a similar way we are
21 doing with the measures of the outcomes based on
22 CMS criteria; importance, feasibility and

1 usability and looking at the magnitude of effects
2 in the previous studies. And then linking the
3 risk adjusters to the outcomes that we actually
4 will be testing and piloting so that we don't
5 have risk adjusters that don't relate well to the
6 outcomes. And we are kind of parsimonious about
7 examining all those variables.

8 But, you know, as has become clear
9 through this webinar, but from your comments it's
10 critical that we engage as many stakeholders as
11 possible, and we very much appreciate your input
12 into this work so that we make it as applicable
13 and relevant to all the groups that we need to
14 work with.

15 DR. ABERY: So, if there is anybody
16 out there in the audience who would be interested
17 in participating in the technical assistance
18 panels that we will be putting together over the
19 next, well, several months and years, you know,
20 you can contact either Renata or me or Amy
21 Hewitt, who serves as co-director, or we can work
22 through our colleagues at NIDILRR, Amanda

1 Reichard is our project officer, to make those
2 connections, because we do want as much community
3 input as Renata has suggested, as possible.

4 CO-CHAIR MONSON: Great. And NQF
5 staff will send out their email addresses to
6 everybody so that we can be in touch with them.

7 Yes, D.E.B.

8 MEMBER POTTER: Hi. This is D.E.B.
9 again. Thank you so much for this presentation.
10 This is the third time I've heard variations on
11 this presentation, and every time it's richer and
12 I have a better understanding of all of the
13 moving parts.

14 One thing I still don't have a good
15 handle on is what is the accountable entity? Who
16 are you holding accountable for the performance
17 of the quality metric?

18 So, there's measures that hold health
19 plans accountable, measures that hold hospitals
20 accountable, measures that hold programs or
21 states accountable.

22 If you could speak a little bit to the

1 accountable entity, because as you pointed out in
2 one of your slides, one of the criterias of
3 importance is a performance gap. And the
4 performance gap is between the accountable
5 entities.

6 So, if all the accountable entities
7 measure at 99 percent or 70 percent, it's not
8 differentiating and helping you to improve.

9 So, if you could speak to that, that
10 would be helpful.

11 DR. TICHA: Yes. Thank you very much
12 for the question. I think there are a couple
13 pieces to that.

14 So, when we were charged with the
15 Center, one of the initial -- one of the major,
16 initial pieces was a focus on developing measures
17 that were psychometrically sound and important.

18 And so, we -- our first -- we have not
19 even reached our second year of the Center. We
20 have been really focused on developing measure
21 concepts that will stand the test of psychometric
22 rigor.

1 Then after we have established some of
2 that, then I think we are going to more closely
3 look at the differing accountability frameworks.

4 You alluded to the high percentages of
5 agreement between the different NQF domain and
6 the ratings. I think that is -- that is
7 important to consider.

8 However, we -- in addition to the
9 quantitative data that you saw up there, we have
10 a very, very rich data set of qualitative data
11 that provides really good information on
12 differentiation among those domains and
13 subdomains, and also that introduce additional
14 subdomains and domains to the framework.

15 And so, I know I'm not quite answering
16 your question, but I think we are sort of in
17 early stages of the Center and that we'll provide
18 initial information within the next, I would say,
19 three to six months.

20 DR. ABERY: Also, to build off what
21 Renata was saying, you know, in the FAL that was
22 issued by NIDILRR, it was made clear that the

1 measurement work that the Center was to do, you
2 know, was to kind of cut across a variety of
3 different entities that are responsible for the
4 quality of home and community-based services
5 ranging from provider organizations to states.

6 And so, we're looking at our work in
7 that way and currently we're doing a fairly large
8 amount of work with the state of Minnesota in
9 helping them to improve the quality of their
10 measurement in an area working with three
11 different regions of the state and have come up
12 with over in about a year period of time, what we
13 believe is an approach that will get at, you
14 know, both the standard -- based upon the
15 standard questions, survey questions asked of
16 individuals, but also will allow the state to
17 dive deeper into the extent to which the supports
18 people are being provided with are truly person-
19 centered and the degree to which they are
20 actually able to achieve some of the life
21 outcomes that they desire.

22 So, on responsible entities, it is

1 going to be -- or our goal is to cut across the
2 different entities. And, again, we are
3 attempting to do this in a way which is
4 consistent with the NQF framework, but also is
5 going to build upon it.

6 CO-CHAIR MONSON: Well, thank you all
7 very much for sharing that with us today. As you
8 can see, this is a group that's very interested
9 in this topic and is -- I know many individuals
10 in this room will be very eager to continue to be
11 engaged with you outside of the role here on the
12 MAP Committee.

13 It's exciting work that you're doing,
14 it's important work. And so, we thank you for
15 what you're doing and for taking the time to
16 speak with us today.

17 DR. ABERY: Thank you very much.

18 DR. TICHA: Thank you.

19 CO-CHAIR MONSON: All right. And so,
20 we're going to take, I'm going to say, a ten-
21 minute break, because we're running a little
22 behind schedule. So, back here at 2:35 Eastern.

1 (Whereupon, the above-entitled matter
2 went off the record at 2:25 p.m. and resumed at
3 2:35 p.m.)

4 MS. BUCHANAN: Hi, all. Thank you
5 very much and welcome back. So, we wanted to
6 make a quick announcement.

7 We originally had on the schedule,
8 voting for inclusion both in the family and the
9 starter set on the CAHPS measure. What we are
10 going to do is we are going to send that via
11 SurveyMonkey tomorrow so people can vote on it,
12 because we don't want to lose quorum and we do
13 want to hear this presentation first. So, just
14 an FYI to keep a lookout for us asking for a
15 vote.

16 And other than that, that we'll have
17 just the --

18 MEMBER POTTER: How will we find out
19 the results?

20 MS. BUCHANAN: Yes. So, they will be
21 emailed through communication. And then, so, if
22 we are going to take away the voting for the

1 measure, we also will be talking, though, about
2 the strategic direction for the duals population.
3 And then we'll open it up for member and public
4 comment. And then we'll adjourn for the day.

5 But prior to that, we are very lucky
6 to have Dr. Kerry Lida, who is the team lead for
7 the testing experience and functional tools
8 demonstration within CMS, and the TEFT
9 demonstration is within the Disabled and Elderly
10 Health Programs Group, Division of Community
11 Systems Transformation.

12 She is also joined by Elizabeth
13 Frentzel, who is a principal research scientist
14 at the American Institutes for Research, with
15 almost 20 years of experience in developing CAHPS
16 surveys, including the HCBS CAHPS, Medicaid
17 CAHPS, home health CAHPS, nursing home family
18 CAHPS and cancer CAHPS pilot version.

19 We also have Coretta Mallery, who is
20 the principal research scientist at AIR and have
21 over five years of experience doing CAHPS survey
22 data analysis. She was the analytic lead for the

1 HCBS CAHPS survey and related measures.

2 And then last, but not least, we have
3 Susan Raetzman, who is the director at Truven
4 Health Analytics and the current TEFT TA lead for
5 the Experience of Care component under which the
6 HCBS CAHPS survey and related measures were
7 developed.

8 And with that, I will turn it over to
9 you all. Just let us know when you want us to
10 move the slides. Thank you.

11 DR. LIDA: Wonderful. Thank you for
12 inviting us to talk with you today about the
13 CAHPS Home and Community-Based Services Survey
14 and related measures that were endorsed by NQF.

15 My name is Kerry Lida and I am
16 delighted to be sharing this area of work with
17 you and very happy that we have expert colleagues
18 on the line with us, including Susan Raetzman,
19 Elizabeth Frentzel and Coretta Mallery.

20 If you could advance to the next
21 slide, please. Today we'd like to cover the
22 following topics; development of the survey,

1 including the need for a CAHPS survey for home
2 and community-based services, HCBS; key features
3 of the HCBS CAHPS survey; National Quality Forum-
4 endorsed measures derived from the survey; state
5 use of the survey and some of the resources that
6 are available for use.

7 Next slide, please. And briefly in
8 the next few slides, we'll be giving an overview
9 -- a very brief overview of the development of
10 the survey. And then we will walk through some
11 examples which we believe will be of interest to
12 this meeting today.

13 Next slide, please. Before we do
14 that, let's talk about why a CAHPS survey
15 focusing on the HCBS setting is important.

16 Historically, Medicaid systems for
17 people who needed long-term services and support,
18 LTSS, had an institutional bias in that services
19 overwhelmingly were provided in institutional
20 settings such as nursing facilities, long-term
21 care hospitals and intermediate care facilities
22 for persons with intellectual and developmental

1 disabilities.

2 However, the percentage of Medicaid
3 LTSS expenditures for HCBS has grown since the
4 early 1980s.

5 By the late 1980s -- 1990s, HCBS
6 accounted for more than 25 percent of the 70
7 billion spent on Medicaid long-term services and
8 supports.

9 And by fiscal year 2014 for the first
10 time, over half of Medicaid's LTSS dollars, 53
11 percent, was spent on community-based supports.

12 With such a large portion of LTSS
13 provided in the community, it is imperative that
14 there be mechanisms for ensuring the quality of
15 care delivered in those settings.

16 Next slide, please. The entire
17 development and testing process beginning in
18 2010, was funded by CMS under two projects. the
19 most recent is the demonstration grant for
20 testing, experience and functional assessment
21 tools, TEFT, in community-based long-term
22 services and supports. Prior to that, it was the

1 National Quality Enterprise, the NQE grant.

2 There are four test components. And
3 each component has different activities and time
4 lines which you will see in front of you.

5 In the upper left quadrant is the
6 Experience of Care Survey component under which
7 test grantees and researchers from Truven Health
8 and the American Institutes for Research test and
9 survey, which contributed substantially to
10 submissions to CAHPS and NQF.

11 The other three quadrants we will not
12 be discussing, but they are available on
13 medicaid.gov if you are interested in further --
14 and those include the functional assessment
15 standardized items, the eLTSS plan standard in
16 collaboration with ONC and the Personal Health
17 Record.

18 Next slide, please. Test grantees
19 participated in the pilot and field tests that
20 were conducted to test for reliability and the
21 validity of the instrument and measures derived
22 from it.

1 This table shows that beneficiaries
2 from up to four HCBS programs in each of the ten
3 test states were surveyed in the pilot and field
4 tests.

5 Individuals and Medicaid HCBS programs
6 in Louisiana and Tennessee participated in the
7 pilot test between October 2013 and October --
8 April 2014.

9 Field testing took place in Louisiana,
10 New Hampshire, Connecticut, Maryland, Minnesota,
11 Colorado, Arizona, Kentucky and Georgia between
12 July 2014 and February 2015.

13 Next slide, please. As noted earlier,
14 the HCBS CAHPS survey felt a critical need in
15 LTSS quality assurance because it focuses on
16 Medicaid, HCBS beneficiary-experienced outcomes
17 and quality of life as the result of receiving
18 services and supports.

19 What distinguishes it from other HCBS
20 surveys is that it was designed to be completed
21 by the broad range of beneficiaries through the
22 Medicaid HCBS programs, including individuals who

1 are frail/elderly, individuals with a physical
2 disability, individuals with an intellectual or
3 developmental disability, individuals with brain
4 injury and individuals with serious mental
5 illness.

6 Next slide, please. This is a very
7 brief summary of approximately six years of work
8 and we have a team who will be available to
9 answer questions you have in any of these areas.

10 The development team follows the CAHPS
11 survey development process, a rigorous and
12 beneficiary-involved process. It is also well-
13 known and highly regarded by developers of
14 experience of care surveys.

15 This diagram outlines the three major
16 phases of the development process. The process
17 of developing and testing the survey instruments
18 began at the formative research stage to identify
19 key domains and constructs. Then the team
20 drafted the survey.

21 In Phase 2, survey development
22 continued with multiple iterations of cognitive

1 testing of the draft survey instrument in both
2 English and Spanish.

3 Once the items were refined, the
4 survey was pilot and field tested on over 3200
5 individuals in 10 states and 26 HCBS programs
6 using both fee-for-service and managed long-term
7 services and supports.

8 In Phase 3, pilot and field test data
9 were analyzed to determine which items worked or
10 did not work allowing the survey to be finalized.

11 The survey instrument receives the
12 CAHPS trademark in June 2016. NQF endorsement of
13 the related measures occurred in October 2016.
14 Survey and measure maintenance activities
15 continue from those points in time.

16 And it is -- as noted in the beginning
17 of this slide, we mentioned the high level of
18 integration and input that we sought from
19 individuals who are participating in this. And
20 it's very unique and it's a very critical survey
21 in this regard and we're happy to speak more
22 about this.

1 Let me hand the presentation now off
2 to Elizabeth Frentzel from AIR, who will
3 continue. Thank you.

4 DR. ROILAND: Operator, is Elizabeth
5 Frentzel on the line? Operator?

6 THE OPERATOR: I do not see her
7 connect-in.

8 DR. ROILAND: All right. Apologies,
9 Kerry. We seem to have lost Elizabeth. Just one
10 moment, please.

11 DR. LIDA: Okay.

12 (Pause.)

13 DR. ROILAND: Elizabeth, if you are
14 logged into the webinar platform - we did have
15 you noted as calling in earlier, but you may have
16 dropped off accidentally. If you could call back
17 in, that would be great.

18 (No response.)

19 DR. ROILAND: Kerry, is there another
20 section of the presentation we could -- I know
21 this is probably an important part of the
22 presentation.

1 Do you just want us to wait for
2 Elizabeth to try to get her back on?

3 (No response.)

4 DR. ROILAND: Kerry?

5 (No response.)

6 DR. ROILAND: Operator, are you still
7 there?

8 (Laughter.)

9 CO-CHAIR MONSON: I'm waiting for
10 someone to say --

11 DR. ROILAND: Hello? All right. Just
12 stand by, please. We're having some technical
13 difficulties.

14 (Pause.)

15 DR. ROILAND: All right. Operator,
16 can you hear me now?

17 (No response.)

18 DR. ROILAND: Operator, we can't hear
19 you, if you can hear me, just so you know.

20 (Pause.)

21 DR. ROILAND: Hi, all. I don't know
22 if you can hear us, but we are having technical

1 difficulties. So, just, if you give us one
2 minute, we will hopefully get this remedied.

3 MS. JUNG: This is just the time we
4 would have waited for the, you know, clickers to
5 work. So, we're just moving it around.

6 DR. ROILAND: Kerry, this is Rachel
7 with NQF, we can hear you now. I apologize, I
8 don't know what happened there for a moment.

9 Just give us one second while we get
10 reset here.

11 MS. FRENTZEL: Great, thank you.

12 DR. ROILAND: All right, Elizabeth,
13 are you on now?

14 MS. FRENTZEL: Yes, I am.

15 DR. ROILAND: All right, thank you.

16 I really apologize about that, but the floor is
17 yours now. And, you can just let us know when
18 you want to advance the slides by just letting us
19 know next slide.

20 MS. FRENTZEL: Thank you.

21 So, next slide?

22 So, the survey is intended to, in

1 reports about a particular HCBS program's
2 performance, these are the beneficiary-reported
3 experiences.

4 The unit of analysis is either the
5 HCBS program or the accountable entity.

6 An accountable entity is the operating
7 entity responsible for managing and overseeing a
8 specific HCBS program within a given state. For
9 example, a managed care organization.

10 The HCBS CAHPS survey was developed so
11 that the comparisons about the quality of
12 services and support can be made across programs
13 or between managed care organizations or other
14 subgroups.

15 Next slide, please?

16 The development process identified the
17 home and community based services and supports
18 and providers that would be appropriate for
19 beneficiary input across the disability and HCBS
20 program spectrum.

21 The services and providers listed on
22 this slide are those that are common across

1 Medicaid HCBS programs with one exception.
2 Although employment assistance services are not
3 offered across all programs, the TEP, or
4 Technical Expert Panel, encouraged the inclusion
5 of items on these services because they are so
6 vitally important for full community
7 participation, especially for working aged-adults
8 served in HCBS programs.

9 Next slide, please?

10 As a result of the pilot and field
11 test analyses, as well as feedback from the TEP -
12 - I'm sorry, I think this was -- is this the
13 slide?

14 So, as a result of the pilot and field
15 test analyses as well as feedback from the TEP
16 and CAHPS consortium, the finalized survey
17 includes the items and measures depicted on this
18 slide.

19 First is a set of three cognitive
20 screening items that help identify individuals
21 who may or may not be able to provide reliable
22 information.

1 These individuals may assent to having
2 a proxy respond to the survey.

3 Next, survey identification items and
4 screening items ensure that the beneficiary
5 answers only questions about the services that
6 they receive.

7 Because not every beneficiary answers
8 all questions, the average survey administration
9 time is 30 minutes.

10 There are 34 items that make up
11 composite measures that will be described later
12 in this presentation.

13 Stakeholders deemed some single item
14 measures as important to retain even though they
15 did not fit into a composite. These include a
16 series of questions that assess a person's unmet
17 needs and physical safety.

18 Six global rating and recommendation
19 items provide information on the person's overall
20 experience with the three main types of staff.

21 There are 15 items that collect
22 demographic information, some of which are used

1 for case mix adjustment.

2 And, finally, a 21 item supplementary
3 employment module is an option for programs that
4 provide employment services.

5 Next slide, please?

6 Now we provide more detailed
7 information about the survey and beneficiaries
8 with cognitive challenges.

9 The survey was designed including
10 question wording and response sets to be
11 accessible to as many HCBS beneficiaries as
12 possible.

13 However, it's also important that
14 those using the results of the survey have
15 confidence in those results.

16 And, for this reason, the survey
17 starts with a three cognitive screening questions
18 shown on this slide. If all three questions are
19 answered in a meaningful way, the interviewer
20 continues to administer the remainder of the
21 survey.

22 If the three questions are not

1 answered appropriately, it is an indication to
2 stop the interview and inquire about a potential
3 proxy respondent.

4 Next slide, please?

5 Here, we provide more information
6 about the survey's incorporation of program and
7 provider-specific terms.

8 On the basis of the formative
9 research, we knew that there were very few
10 uniform naming conventions for providers across
11 programs in terms that individuals used in
12 referring to their providers.

13 Thus, the survey was designed so that
14 sponsors can incorporate program-specific terms
15 for categories of staff and provider-specific
16 terms for individual staff.

17 The preferred terms can be used
18 throughout the survey. You can see the
19 bracketed, italicized text that alerts the person
20 administering the survey to administer -- to
21 insert program-specific term for these types of
22 staff.

1 Next slide, please?

2 Now we provide information about
3 another survey feature aimed at increasing
4 beneficiary participation. On the basis of
5 findings from the cognitive testing as well as an
6 experiment conducted as part of the field test, a
7 simplified response option was determined to be
8 accessible for some individuals.

9 Using both response modes allows for
10 more people to participate in the survey,
11 including individuals with intellectual or
12 developmental disabilities.

13 This slide shows the alternate
14 response approach in the survey itself. The
15 interviewer starts with a standard CAHPS response
16 option of never, sometimes, usually or always.

17 If the respondent has difficulty using
18 that question and response format to answer, the
19 interviewer then asks the alternate version.

20 The interviewer does this three times,
21 and if the respondent prefers the alternate
22 version, the interviewer then uses only the

1 alternate version for the rest of the survey.

2 Next slide, please?

3 The HCBS CAHPS survey asks about
4 several categories of HCBS services, some of
5 which respondents do not receive.

6 To help interviewers ask only the
7 relevant questions, the instrument was developed
8 with skip patterns imbedded throughout.

9 The survey also was developed with
10 addition skips related to screener questions.
11 This helped to ensure that specific experiences
12 could be identified on which programs would be
13 able to act.

14 In the examples shown on this slide,
15 there is a set of questions focused on whether
16 the individual goes without help in bathing or
17 getting dressed because personal assistance staff
18 are not there to help.

19 The first screener question in the
20 series asks whether the person needs help from
21 the personal assistance staff to bathe, shower or
22 get dressed. If the person says no, in other

1 words, that he or she has no need for help, the
2 interviewer is instructed to skip the next three
3 items and move on to an item on personal privacy.

4 If the interviewer -- if the
5 beneficiary says yes to the screener question
6 about needing help, then up to two additional
7 follow up questions are asked to elicit
8 information on an unmet need.

9 Next slide, please?

10 Because survey response rates are an
11 important issue, we want to share with you the
12 pilot and field test results.

13 The overall response rate was about 22
14 percent with the highest response rate, over 30
15 percent among participants of programs serving
16 individuals who are frail elderly and individuals
17 with a physical disability.

18 The lowest response rate, about 10
19 percent, was among participants of programs
20 serving individuals with an intellectual or
21 developmental disability.

22 In addition, in the pilot and field

1 tests, participants of different programs
2 preferred different modes.

3 Next slide, please?

4 Although the HCBS CAHPS survey was
5 intentionally designed to be as accessible as
6 possible, survey vendors indicated that guardians
7 could act as gatekeepers by refusing on behalf of
8 the beneficiary or wanting to be their proxy.

9 Survey vendors also reported that
10 other individuals in the person's life were
11 willing to respond to the survey as proxy
12 respondents.

13 Thus, part way through the field test,
14 we began allowing proxy responses.

15 For the purposes of the pilot and the
16 field tests, a proxy respondent refers to any
17 help that the respondent received in completing
18 the survey.

19 This ranged from answering all
20 questions for the respondent to providing
21 prompts, translation or help with communication
22 technology.

1 This table presents numbers and
2 percentages of proxies for each HCBS population
3 represented in the pilot and field tests.

4 As you can see, across the board,
5 proxies were used to some extent and there was
6 substantial variation and use by population and
7 by state.

8 These results are likely an
9 underestimate of proxy respondent participation
10 had they been allowed throughout the entire data
11 collection period.

12 Next slide, please?

13 Going forward, proxy respondents are
14 being allowed by CMS for administration of the
15 HCBS CAHPS survey. This flexibility has a few
16 implications for survey sponsors.

17 For example, it's up the sponsoring
18 entity to decide whether to use proxies and which
19 proxies to include.

20 There are certain qualities that make
21 an individual more likely to be a good proxy
22 respondent.

1 If a proxy respondent is being used,
2 the IRB may require that the assent of the
3 beneficiary as well as the consent of the proxy
4 be obtained and documented.

5 If proxies are used sponsoring
6 entities introductory script for reaching out to
7 the beneficiaries will need to allow for talking
8 with proxies. This script should reflect
9 decisions that the sponsor makes about which
10 proxies to include.

11 While fielding the survey, sponsors
12 may want to monitor the percentage of surveys
13 that are completed by the proxies.

14 Finally, the data analyses should
15 adjust for the use of proxies.

16 Next slide, please?

17 Once an interview has been completed,
18 there are a few interviewer questions that ask
19 about proxy respondents. The questions shown on
20 this slide are used in the HCBS CAHPS survey to
21 distinguish HCBS (a) beneficiaries who were not
22 helped in completing the survey from either

1 beneficiaries who received assistance from
2 another person in completing the survey; or, (b)
3 beneficiaries whose survey was completed by
4 someone responding on their behalf.

5 And, now, this goes over to Coretta.

6 DR. MALLERY: Great, thanks,
7 Elizabeth.

8 Next slide, please?

9 So, I'm going to give you a brief
10 overview of the NQF endorsed measures derived
11 from the HCBS CAHPS survey.

12 So, next slide, please?

13 Okay, so the HCBS CAHPS survey items
14 provide information about specific domains of the
15 HCBS experience.

16 The HCBS CAHPS survey has 34 items
17 that support seven scale measures and 12 items
18 that support single item measures from the
19 domains shown here.

20 So, this slide gives a nice overview
21 of our scale measures and the different domains.

22 After the composites were identified

1 in the analyses, the developer team went back to
2 a group of beneficiaries and talked with them
3 about the best labels of each of the composites.

4 So, this slide reflects these labels
5 for the final set of composites.

6 The next several slides describe each
7 scale measure and the survey items that make up
8 each of them as well as the single-item measures.
9 And, each of these are NQF endorsed measures.

10 Okay, so, this slide shows the first
11 composite, staff are reliable and helpful. There
12 are six items that pertain to the personal care
13 attendant, behavioral health staff and/or the
14 homemaker.

15 These include whether staff come to
16 work on time, whether staff work is done when
17 they're supposed to and how long staff makes sure
18 beneficiary has enough privacy when bathing and
19 dressing.

20 Next slide, please?

21 Okay, so the next composite, staff
22 listen and communicate well has 11 items.

1 These items focus on aspects of
2 service and support such as how often staff show
3 courtesy and respect and how often staff listen
4 carefully to the beneficiary.

5 And, I'm just giving a brief overview
6 because you all can -- will have access to the
7 slides and can see each item in each measure.

8 Next slide, please?

9 Okay, so the next measures, case
10 manager is helpful, so, this slide shows the
11 first three items in this composite, addresses
12 things such as whether the case manager works
13 with beneficiary when he or she asks for help
14 with getting changes to services and a few other
15 constructs.

16 Next slide, please?

17 Okay, so, this slide shows that the
18 composite, choosing the services that matter to
19 you consist of items on whether the person's
20 service plan includes things that are important
21 to the beneficiary, whether the staff know what's
22 in the person's service plan, including the

1 things that are important to the beneficiary.

2 Next slide, please?

3 This slide shows that transportation
4 to medical appointments composite consist of
5 items about how often the beneficiary has
6 transportation to medical appointments, whether
7 the beneficiary is able to get in and out of the
8 ride easily and how often this ride arrives on
9 time.

10 Next slide, please?

11 So, there are three items in the
12 personal safety and respect composite that ask
13 the beneficiary about whether there is a person
14 with whom they can talk if someone hurts them or
15 does something to them that they do not like,
16 whether any staff takes the beneficiary's money
17 or their possessions without first asking,
18 whether they have staff that yell, swear or curse
19 at them.

20 Next slide, please?

21 Okay, so, this slide shows the
22 composite, planning your time and activity. And,

1 this is a community integration measure that asks
2 about how often the beneficiary gets together
3 with family members or friends who live nearby if
4 they want to do so, how often the beneficiary
5 does things in the community that he or she likes
6 when he or she wants to do and similar
7 constructs.

8 Next slide, please?

9 Okay, so, in addition to the seven
10 composite measures, there are global ratings,
11 measures and three recommendation measures that
12 are supported by the HCBS CAHPS survey.

13 Both the global ratings and
14 recommendations are specific to three different
15 types of service providers shown here, so
16 personal assistant, behavioral health staff,
17 homemakers and case managers.

18 Next slide, please?

19 So, in our psychometric analyses,
20 there were 13 items that were not part of a
21 composite that the Technical Expert Panel felt
22 that should -- that were important enough to be

1 retained in the survey as standalone items that
2 were then, we put forward a standalone measures.

3 This slide shows a subset of these
4 that were submitted to NQF and endorsed. So,
5 these include measures that address unmet needs
6 and physical safety.

7 Okay, now, Susan Raetzman will be
8 talking about potential uses of the survey.

9 MS. RAETZMAN: Thank you, Coretta.

10 Next slide, please?

11 MEMBER ZLOTNIK: Yes, can I just ask
12 a question before you go on?

13 Related to the global ratings related
14 to workforce issues, I had a question about
15 survey item 35, global rating of personal
16 assistants and behavior health staff.

17 Those two things sound very different
18 to me, unless you are just talking specifically
19 about kind of more like residential staff that
20 might be in a behavioral health setting.

21 The behavioral staff could be
22 everything from a psychiatrist to someone who is

1 a group home staff person.

2 So, I don't -- that's a very big area.

3 So, is there a definition of it?

4 DR. MALLERY: Yes, so, Elizabeth, I'm
5 not sure if there might be --

6 MS. FRENTZEL: Yes, I can answer it.

7 It's the behavioral health staff and
8 these are the people who are providing services
9 in home. So, they might be, for example, queuing
10 an individual to help them know the next
11 behavior. It's not -- it would not include
12 psychiatrists or anyone highly clinical.

13 MEMBER PARKER: But, how would the --
14 hi, this is Pam Parker on the Committee -- how
15 would the person know what you're talking about?

16 MS. FRENTZEL: In the initial --
17 there's an initial set of questions on providers
18 and they provide definitions there.

19 MEMBER PARKER: Well, I'd just say,
20 within my experience, I had the same question
21 about case manager, because there are multiple
22 levels of case management in these programs and

1 I'm not sure which one the person thinks we would
2 be talking about.

3 And, we've used, actually, in
4 Minnesota, in the CAHPS at the state level for
5 other programs, the part of the Medicaid program
6 for the big CAHPS that's done, we've used
7 questions on care coordination and case
8 management like type questions and we know that
9 there's a lot of fuzziness around that.

10 We've done focus groups on that. And,
11 we know that people define case managers as
12 everybody from their family friend to their
13 doctor to everybody in between.

14 And, so, I'm just saying that, you
15 know, just because you put in the survey, maybe
16 not clear to the member that's looking at the
17 survey, even if you explain it to them.

18 MS. FRENTZEL: Absolutely.

19 MEMBER PARKER: Yes.

20 MS. FRENTZEL: And, that's what we
21 found in the focus groups and that's why, you
22 know, we've -- after the cognitive screening

1 questions, there are all these -- there's several
2 program questions to really narrow it down
3 because there's such variation.

4 Now, with case managers, it was more
5 of a titling issue, not so much kind of the work
6 they do. So, we have a definition for case
7 manager for personal health staff or behavioral
8 staff and homemaker staff and, so, that, because
9 of the variation.

10 But, you're right. And, if they could
11 have potentially two case managers --

12 MEMBER ZLOTNIK: Some have 23 case
13 managers.

14 MS. FRENTZEL: A single person could
15 have 23 case managers?

16 DR. JACKSON: This is Beth Jackson,
17 I'm also on the -- I was on the development team.

18 And, because the accountable entity is
19 typically a program, the sponsor of the survey
20 would be able to say this is what we call a case
21 manager in this program.

22 And, you know, typically, my

1 experience has been that a person has one case
2 manager in an HCBS program.

3 Granted, that an individual could have
4 more than one case manager across programs and be
5 enrolled in more than one program, but I think it
6 would be very clear to the individual what
7 program they were being surveyed about.

8 And that, in fact, it's even possible
9 to customize the survey in such a way that
10 actually talking about, you know, your case
11 manager and the person's name. So, I think that
12 helps.

13 And, in terms of the behavioral health
14 staff, it's really behavioral health staff coming
15 into the home to help with ADLs and IADLs.

16 I don't know if that helps answer your
17 questions or not.

18 MEMBER ZLOTNIK: I mean, I think it
19 does by using the name because I think I've
20 worked with a lot of people who really can't keep
21 track of who belongs to what program who are
22 coming into their house or what they're role is.

1 CO-CHAIR MONSON: Well, and, actually,
2 even within a program like, in Ohio, for
3 instance, if you're in the MMP and you're over
4 65, you have two case managers. You have a
5 health plan case manager and you have a AAA case
6 manager.

7 Same thing in Kansas, if you are in
8 the LTSS program there, you've got if you're an
9 individual with IBD, you've got a targeted case
10 manager from the county and you've got a health
11 plan case manager. So, you're definitely going
12 to have two.

13 MEMBER ZLOTNIK: Yes, and if I could
14 just say, where are the term case manager is
15 often also used is at the provider level.

16 So, if you have a personal care
17 provider and another kind of behavioral health
18 provider and, you know, several other kinds of
19 service providers, that's where you might find a
20 home health like skilled nursing, you'll find a
21 case manager.

22 And, then you've got, in addition, you

1 might have a home community based case manager
2 and an MMP or a D-SNP case manager or usually
3 called care coordinator or something else, but
4 that's where --

5 But, I will say that I think your idea
6 of trying to get the name of the person is a good
7 one. We did do that in Minnesota in our early
8 testing of not CAHPS survey, but another consumer
9 survey that we were trying and that did help.

10 But, it was very difficult to keep
11 track of the name because, depending on which one
12 you're talking about, because you've got to have
13 that bin ahead of time in the survey. And, if
14 you're administering the survey by mail or
15 something, you know, that can change by the time
16 you get it printed up.

17 I don't even know how you do it
18 exactly, you know, it takes manual work to do it
19 then. So, it's difficult.

20 CO-CHAIR MONSON: Is it relevant to
21 this particular topic, Beth? Because Tom has
22 been waiting.

1 MEMBER POTTER: Yes, Beth, maybe you
2 could day, this is D.E.B. Potter, a little bit
3 about how this survey is administered using a
4 computer-assisted application and all of that.
5 That might be helpful.

6 DR. JACKSON: Yes, yes, it was
7 designed to be face to face or by phone. So,
8 it's designed to be CATI, computer-assisted
9 telephone interviewing, or CAPI, computer-
10 assisted program interviewing.

11 So, it's not -- given the complicated
12 skip patterns and given the desire to tailor it
13 to the program and the individual as much as
14 possible, doing that with a male survey would be
15 virtually impossible.

16 We were also counseled early on by
17 members of our TEP to have this be actually an in
18 person. They felt with the HCBS population,
19 particularly with so much cognitive impairment as
20 well as hearing impairments that it would be
21 important to do this survey face to face.

22 CAHPS does require at least two modes

1 of administration and we did add the telephone
2 interviewing, which we found, and which states
3 are finding now, at least, well, I'll say at
4 least one state is finding in the test program
5 that individuals in these programs are -- in some
6 of the programs are preferring the telephone
7 interview as opposed to being visited.

8 So, it's CAPI or CATI, CATI or CAPI is
9 highly recommended and not telephone, I'm sorry,
10 not mail. Does that do it?

11 MS. FRENTZEL: Yes, it did.

12 CO-CHAIR MONSON: So, why don't we go
13 to Tom? We've got about 13 minutes left for this
14 topic. So, we'll go to Tom's question then we'll
15 keep going.

16 MEMBER LUTZOW: Yes, this Tom Lutzow,
17 iCare, Wisconsin.

18 Self-directed support is a big thing
19 in Wisconsin. We're a FIDE SNP, 30 percent and
20 it's growing. Maybe this year, it will reach 40
21 percent of the members of self-direct some of
22 their home and community-based waiver services,

1 especially personal care, homemaking and support
2 of home care kinds of things.

3 Do you make note of that? It's a co-
4 employment situation, there's a fiscal agent that
5 is the employer of record but pretty much, the
6 member picks their own worker.

7 And, even sometimes, when we might
8 otherwise prefer they pick someone else, it's a
9 relative, maybe even someone who is, you know,
10 has a court record that would otherwise not make
11 the cut. But, because it's a matter of
12 preference, they're selected and hired.

13 Where is that accommodated here?

14 MS. RAETZMAN: So --

15 MS. FRENTZEL: Go ahead, Susan.

16 MS. RAETZMAN: This is Susan Raetzman.

17 The survey accommodates it by not
18 actually making a distinction. The questions can
19 be asked for a person who is, you know, providing
20 services under that arrangement as well.

21 If the survey sponsor wants to be able
22 to identify those surveys when they're doing the

1 analysis, they could add that information to
2 their analytic file so that they could look at
3 that separately.

4 CO-CHAIR MONSON: Okay.

5 Do you have more of your presentation?

6 MS. RAETZMAN: Yes, we have a few more
7 slides.

8 CO-CHAIR MONSON: Okay.

9 MS. RAETZMAN: And, I'll go fast.

10 So, could you go to the next slide,
11 please?

12 So, this is just a brief review of
13 some of the aspects of the survey that states are
14 encouraged to consider in their thinking about,
15 you know, whether the CAHPS -- HCBS CAHPS survey,
16 you know, fits into their needs.

17 So, it's the person centeredness, the
18 fact that you can use the survey with a broad
19 range of individuals with disabilities and do
20 that with a single instrument, you know, across
21 these different programs.

22 It's designed to be as accessible as

1 possible to all beneficiaries through a variety
2 of design features that we've talked about.

3 It aligns with CAHPS. It supports
4 several quality metrics such as the NQF ones and
5 there's an opportunity for users to also add
6 their own specific questions that they're
7 interested in or as a supplemental employment
8 module.

9 And, because it is provided by CMS to
10 the public, there's no cost to access the
11 instrument or the supporting documents.

12 Next slide, please?

13 We have also been explaining that this
14 CAHPS -- the HCBS CAHPS survey can be used in a
15 variety of ways for program quality management.

16 First, it can help to document program
17 successes. In addition, by fielding the survey
18 over a short period of time, users can get a
19 point in time performance snapshot to identify
20 areas needing improvement.

21 And, the, of course, you would want to
22 do further investigation to determine the cause

1 of any problems identified.

2 Another way to use the survey is to
3 repeat survey administrations in order to track
4 performance over time and monitor changes.

5 For example, before and after
6 implementation of a program improvement project.

7 And, provided there's a sufficient
8 beneficiary sample for each program or subprogram
9 group, the survey can make comparisons among
10 programs serving individuals with different types
11 of disabilities.

12 It can be used to convey performance
13 information to a variety of stakeholders within
14 the organization, beneficiaries, providers, even
15 state legislatures.

16 And, because the measures align with
17 some of CMS's quality requirements, the survey
18 can assist states engage in compliance with
19 regulatory requirements.

20 Next slide, please?

21 So, we do have some examples of state
22 uses. Right now, there are seven grantees from

1 the test states that are demonstrating use of the
2 survey in their HCBS programs.

3 And, their plans range from comparing
4 performance across programs to identifying
5 quality improvement opportunities, to exploring
6 whether future managed LTSS programs should use
7 the instrument.

8 We have one grantee that is further
9 studying response rates from different
10 administration modes including an online version.

11 And, we have another grantee, the
12 State of Connecticut, that is using the survey to
13 set quality benchmarks for performance incentive
14 payments to case management agencies.

15 And, if we go to the next slide, I
16 just have a little bit of information about their
17 initial results.

18 They are the furthest along, and
19 that's why they've been able to share their
20 results to date.

21 They are focusing on three waiver
22 programs, those serving older adults, individuals

1 with physical disabilities, that's their personal
2 care assistance program, and individuals with
3 brain injury.

4 They let the participants choose
5 whether to take the survey over the phone or in
6 person and they allowed both assisted surveys as
7 well as proxies to complete the survey.

8 Next slide, please?

9 So, this slide shows preliminary
10 response rates from Connecticut. These are in
11 the 60 to 70 percent range at the bottom of each
12 column for two of the populations.

13 And, Connecticut recently updated that
14 the response rate for the brain injury group was
15 about 61 percent. And they attribute their
16 response rates, first and foremost, to allowing
17 the assistance with the interviews and also proxy
18 respondents.

19 Next slide, please?

20 And, then, this slide of Connecticut's
21 preliminary participation results indicates that,
22 when given a choice of survey mode, more than 9

1 or 10 are choosing telephone. I think it's more
2 like 95 percent actually.

3 Among the brain injury population,
4 just under 20 percent have been in person. So,
5 the majority still prefer the telephone option.

6 And, Connecticut indicates that people
7 who prefer an in person option are usually those
8 with a communication issue where they need to
9 meet in person and also the assisted interviews
10 are sometimes preferred to do in person.

11 And, this slide also shows that the
12 PCA waiver participants were most likely to
13 complete the survey by themselves compared to
14 older adults.

15 And, again, in terms of the brain
16 injury group, about 65 percent completed it alone
17 as opposed to having either a proxy or some help.

18 And, the last slide is just a resource
19 slide in terms of -- yes, just different places
20 that people can go for more information about the
21 survey.

22 And, that's it.

1 MEMBER POTTER: Hi, this is D.E.B.
2 Potter again.

3 Is this Truven mailbox still up to
4 date? I've got other Truven contractors that now
5 have different email addresses. So, I bring that
6 to your attention.

7 DR. JACKSON: Yes, we are aware of
8 that. We have not yet migrated that mailbox, but
9 we will. We are working with CMS to make sure
10 that it is seamless. Thanks for noticing that.

11 MEMBER PARKER: Hi, this is Pam,
12 again.

13 I'm quite interested and excited about
14 the -- you're doing a couple of different things
15 in here than what we've heard the standard CAHPS
16 approach. Now, I wish that Stacey was still
17 here, Stacey from CMS.

18 But, first of all, the fact that
19 you're allowing someone to translate it verbally.
20 I know that the regular CAHPS methodology just
21 has been, you know, absolutely opposed to that.

22 And, I think this is so important for

1 this population and not just having the
2 instrument in a different language, that isn't
3 all that useful, but having someone to be able to
4 do it, you know, verbally.

5 And, of course, then the other is that
6 you're doing it by telephone and you're allowing
7 proxies. So, the proxies, you know, actually
8 administering it by telephone with a person or in
9 person, but I think telephone's the most
10 important.

11 And, then, the other one in terms of
12 the language.

13 In Minnesota, we were doing a project
14 where we've been trying to -- we cover much of
15 the same population with the regular CAHPS and
16 we've integrated the Medicare and the Medicaid
17 CAHPS survey instruments with some success,
18 though, because of these methodologies that CMS
19 insists on, we don't really -- oh, here's Stacey
20 -- we don't get to -- Stacey --

21 MEMBER LYTTLE: Just in time.

22 MEMBER PARKER: What I was excited

1 about here is, I was hoping that what they're
2 testing here with proxies, the language and the
3 in person or on the phone surveys, you know,
4 being able to use additional people, this would be
5 so good for so many dual eligibles across the
6 country if that testing, you know, that they've
7 done now could be transmitted to other CAHPS
8 documents like for the MMPs and like Minnesota
9 with all its, you know, immigrant seniors that
10 are left completely out of these surveys.

11 MEMBER LYTTLE: If only that call had
12 lasted two minutes longer.

13 So, I think the short answer is it's
14 not that easy to translate it to the other CAHPS
15 surveys. We have been in discussion with like
16 the Medicare CAHPS people and others about what
17 it would mean to do some different testing and to
18 use testing that we've seen elsewhere.

19 But, survey order and things that we
20 all know about come into play then.

21 However, we have been in MMCo trying
22 to figure out just where this HCBS CAHPS survey

1 fits and how we can better use the information
2 that it presents because of our population with
3 the MMPs and others.

4 So, it's definitely on our radar and
5 something we've been thinking about because it's
6 information we don't have and we really want,
7 number one.

8 And, number two, because it's done all
9 the testing. So, we know that it works as it's
10 structured. So, we're working on it. I don't
11 know if it gets to the Minnesota issue because
12 there's several questions that you all asked and
13 that the plans asked that are a little different.
14 But, we are looking into how to utilize what's
15 available there.

16 MEMBER PARKER: Yes, and if I could
17 just add that, you know, there is the issue then,
18 too, of the juxtaposition of just how many CAHPS
19 do these poor people have to have?

20 And, in this case, let's say it's, you
21 know, well, Minnesota's the only that's tried to
22 integrate the Medicare and Medicaid so Medicaid

1 may use the CAHPS and Medicare may use it. And,
2 there may be in this field at the same time and
3 then you have this third CAHPS of this one being,
4 you know, discussed and proposed.

5 And, you know, that reduces response
6 rates terribly.

7 MEMBER LYTLE: And, that's our concern
8 that --

9 MEMBER PARKER: Yes.

10 MEMBER LYTLE: -- the survey burden is
11 just too much --

12 MEMBER PARKER: Right.

13 MEMBER LYTLE: -- when we say take
14 these for --

15 MEMBER PARKER: So, there's got to be
16 some kind of hierarchy or some plan around that.

17 But, then -- and then, the other last
18 thing I was going to say was I think everybody
19 should know and maybe you all are expert enough
20 to know this, but I think it's pretty atrocious,
21 I have to say, I know Stacey knows how we feel
22 about this, that when there isn't even a real

1 language block on the CAHPS that, you know, has
2 in different language of what this item is.

3 And, when we had to switch from the
4 Medicaid CAHPS to the Medicare, they made us use
5 all the Medicare approaches to the CAHPS. And,
6 so, we couldn't put a language block on saying,
7 this is, you know, in many different languages
8 saying that this is, you know, even if you don't
9 fill this out, it's okay and but it is.

10 CO-CHAIR MONSON: Yes.

11 MEMBER PARKER: So, they don't know
12 what it is. They get it and they know that they
13 don't have to fill it out, that's stated. But,
14 it doesn't say what it even is or tell you
15 anywhere to go and get help for it or anything.

16 So, it's really, I think, such a poor
17 way to get at some of the frailest and sickest
18 and most disadvantaged and health legacy
19 disadvantaged folks that we have.

20 CO-CHAIR MONSON: Okay, we have time
21 for one more comment.

22 MEMBER LAKIN: You allow proxy

1 comments sort of I gather you leave that up to
2 the program.

3 I just wonder to what extent you've
4 studied the sort of the inter-rater reliability
5 between primary service respondents and those who
6 respond as proxies?

7 The evidence in -- with some surveys
8 that have looked at that suggest they're not at
9 all equal and they're somewhat idealized by the
10 proxy as compared with a service recipient.

11 Is that something you've looked at and
12 put -- if so, do you give that advice to people
13 who might be making a decision about using proxy
14 respondents?

15 I'm particularly concerned with 50
16 percent of the respondents for people with
17 intellectual and developmental disabilities are
18 not service recipient.

19 DR. MALLERY: This is Coretta Mallery.

20 And, we did look at that. And, I
21 could give more specific details on, I believe,
22 but I'm just going off recall, that only one of

1 the measures was higher for proxy respondents.
2 But, I'll need to dig back and find which report
3 that was.

4 But, I agree that there are, you know,
5 there's a lot of research out there that shows
6 that proxies may respond more positively than the
7 beneficiaries.

8 So, what we would recommend is
9 absolutely taking a look at that if you were
10 including proxies and we would also recommend
11 including it as a case mix adjuster. So, you
12 know, including whether or not a proxy responded
13 on behalf of the beneficiary. So, but the scores
14 could be adjusted for that.

15 CO-CHAIR MONSON: Clarke, did you have
16 something burning to say?

17 (OFF MICROPHONE COMMENTS)

18 CO-CHAIR MONSON: Okay. Got it.

19 All right, well, thank you Kerry and
20 team. We appreciate you sharing with us today
21 and, you know, it'll obviously be very helpful
22 for us as we consider this from a voting

1 perspective.

2 And, so are we not voting now?

3 MS. MUKHERJEE: So, no. What we'll do
4 is we'll vote via SurveyMonkey and it's going to
5 go out, so please look at your email and there'll
6 be two questions.

7 One for inclusion into the duals
8 family of measure.

9 And, two, for inclusion to the starter
10 set.

11 So, instead of voting now, just for
12 the sake of getting everybody's voices and some
13 people had to leave, we're going to send out a
14 SurveyMonkey voting.

15 MEMBER ROSS: I did want to highly
16 encourage us to endorse this measure. This is a
17 CAHPS trademark. This is already National
18 Quality Forum endorsed.

19 The MAP report to CMS, two of the six
20 high-value measure areas are patient-reported
21 outcomes and patient experience.

22 This is a high priority of not only

1 the Consortium for Citizens with Disabilities,
2 but the Disability and Aging Collaborative that
3 Joe Caldwell chairs with NCOA.

4 So, this is a big priority that's been
5 in the works for quite a few years that the
6 advocate and provider community-based provider
7 community thinks is really valuable.

8 And, so, I encourage you all to vote
9 yes.

10 CO-CHAIR MONSON: So, even though
11 we're not voting, I do think -- do other people
12 want to chime in about perspectives on the CAHPS?
13 Pro? Con? Yes, go ahead.

14 MEMBER LUTZOW: There might be 11
15 votes here right now.

16 (OFF MICROPHONE COMMENTS)

17 CO-CHAIR MONSON: We can -- okay, we
18 can vote. So, therefore, just -- but still,
19 again, does anyone have any more commentary on
20 the measures themselves before we vote?

21 Yes, Charlie?

22 MEMBER LAKIN: You know, in general,

1 I'm in support of this. I'm not sure -- what are
2 voting for an instrument in this case? Are we
3 voting for composite measures? Are we -- I don't
4 know quite what we're endorsing.

5 MS. MUKHERJEE: So, it's the measures.
6 It's the measures.

7 CO-CHAIR MONSON: All of them?

8 MS. MUKHERJEE: All of them, yes.

9 MEMBER LAKIN: The ones that were
10 endorsed not --

11 MS. MUKHERJEE: Endorsed.

12 MEMBER LAKIN: -- the whole survey,
13 you need to go back and show them what --

14 CO-CHAIR MONSON: Yes, can we see
15 which ones?

16 MEMBER LAKIN: -- need to clarify.

17 MS. MUKHERJEE: So, do you guys want
18 to screen share 2697, the --

19 (OFF MICROPHONE COMMENTS)

20 MS. MUKHERJEE: Yes, so, we're voting
21 on all the measures that came through and were
22 endorsed. And, under 2967 and we're screen

1 sharing. And, there are a lot of measures, but
2 this is not a survey, these are sort of
3 questions.

4 CO-CHAIR MONSON: And, they were
5 endorsed by which committee?

6 MS. MUKHERJEE: The PFCC, Person and
7 Family Centered.

8 CO-CHAIR MONSON: Was there any -- do
9 we know, was there any commentary from that group
10 that we should be aware of?

11 MS. MUKHERJEE: Also, for a quick
12 reference, it's one on the slide in the
13 PowerPoint, so if you want to look at the
14 PowerPoint, if you have it on your desktops.

15 DR. ROILAND: So, while we're getting
16 everything pulled up there, I can give you a
17 brief summary of the issues that the Committee
18 went through when they reviewed the measure.

19 The first round of evaluation at the
20 in person meeting of the PFCC Standing Committee,
21 there was a lot of questions around the which --
22 how the measure would be applied to an

1 organization. Basically, who would be held
2 accountable for the measure.

3 And, so, the developer provided
4 clarity around that saying that -- I'm sorry, let
5 me pull this up here, I don't think we're
6 loading.

7 CO-CHAIR MONSON: Okay, so, which one
8 -- when we're looking on your screen, is it the
9 recommendation measures that we're looking at or
10 the global ratings measures or all of them?

11 MS. ROILAND: so, all of these
12 measures are considered NQF endorsed underneath
13 the NQF Number of 2967. There are 19 measures, I
14 believe. You might need to scroll down a little
15 bit, Madison. Sorry, can you scroll back up,
16 let's start from the beginning.

17 So, there are scale measures. Those
18 are the measures that they went over in the first
19 part of their presentation. So, they're a very
20 number of items that are grouped together to
21 create a scale measure. There are seven of
22 those.

1 Like they said in the presentation,
2 they are, beginning with number one, staff are
3 reliable and helpful, staff listen and
4 communicate well, case manager is helpful,
5 they're able to choose the services that matter
6 to them, they have access to transportation to
7 medical appointments, another scale related to
8 personal safety and respect and then planning
9 your time and activities is another scale
10 measure.

11 Then, they move on to three global
12 ratings measures and these are global ratings of
13 personal assistance and behavioral health staff,
14 global rating of the homemaker staff and global
15 rating of the case manager.

16 We had some discussion around two of
17 those three.

18 Then, there are three recommendation
19 measures. Would you recommend your personal
20 assistant or behavioral staff to family and
21 friends? Would you recommend homemaker staff to
22 family and friends? Would you recommend case

1 manager?

2 Then, there are five measures related
3 to unmet needs. They're on dressing and bathing,
4 preparation -- meal preparation, medication
5 administration, toileting and other household
6 tasks.

7 One physical safety measure, if you
8 can scroll down a little bit, Madison, talking
9 about harm from the staff.

10 And, so, those are the 19 measures.
11 So, if these measures -- these measures are
12 derived from the items on the HCBS experience of
13 care survey, or the CAHPS survey, I'm sorry.

14 So, the measures are derived from that
15 survey and each of these are endorsed measures
16 under the -- under NQF's approach to endorsing
17 measures derived from the survey.

18 MS. JUNG: And, I can read the summary
19 of what the Committee said. Would you like that?

20 So, this for the CAHPS survey. This
21 new PRO-PM is a package of 19 different measures
22 calculated from data from a newly developed

1 experience of care survey focusing on HCBS
2 programs.

3 Numerous challenges were identified
4 with this measures submission including level of
5 accountability and variation in the types of
6 programs and services offered both across and
7 between states.

8 The developer noted that the survey
9 and reporting of the measures are being
10 introduced for voluntary use by states and
11 relevant programs and would help programs
12 identify areas for quality improvement
13 interventions.

14 Committee members with experience in
15 this area noted that what matters to consumers is
16 that their needs are met, not who is meeting
17 them.

18 The Committee decided to vote on
19 evidence all together and then split the measure
20 into five measure domains and vote on each of the
21 domains separately for performance gap and the
22 remaining criteria.

1 The performance and testing data
2 submitted for these measures were limited due to
3 the pilot testing of the survey so the Committee
4 found it challenging to understand the
5 opportunity for improvement performance gap and
6 reliability of some of the domains.

7 The Committee provided recommendations
8 to the developer on the opportunities to address
9 some of the data challenges. However,
10 ultimately, two of the measure domains failed
11 performance gap and the remaining measures failed
12 on reliability.

13 The Committee encouraged the
14 developers to determine if alternate testing
15 procedures might be better -- might better
16 differentiate programs and better support the
17 reliability of the metrics.

18 And, there is a lot more. Let me see
19 if there's a summary. I can keep reading.

20 DR. ROILAND: Would it be better just
21 for us to share this with folks and then we can
22 still vote via survey so you have time to review

1 it better or what would everyone be most
2 comfortable with at this point?

3 MEMBER ZLOTNIK: Could you just
4 clarify what you're asking us to vote on to add
5 it to our family of measures?

6 DR. ROILAND: It would be -- so, we're
7 asking you vote on Measure NQF Measure 2967 and
8 that measure number encompasses all 19 measures
9 from the survey that are created from the survey.

10 DR. ZLOTNIK: Right, but are we voting
11 on it to add it to our family of measures?

12 DR. ROILAND: Well, yes, we're voting
13 on that. But, then, yesterday, the issue also
14 came up that someone wanted to propose also
15 adding it to the starter set, so we're going to
16 ask you to vote on those two things.

17 DR. ZLOTNIK: Thank you.

18 MEMBER PARKER: Could you also just say
19 something about the scaling? Is it typical
20 CAHPS? Is it, you know, it says yes and no and
21 then there's something in between and where is
22 the cut off?

1 DR. ROILAND: It's different for each
2 item. So --

3 MEMBER PARKER: Yes, it's something
4 like never, sometimes, usually, always.

5 MEMBER HAMMEL: But, then they have an
6 alternative.

7 CO-CHAIR MONSON: So, do people -- are
8 there -- do people have concerns about these
9 measures? Let's just start there.

10 Yes, Joy?

11 MEMBER HAMMEL: I didn't have concerns
12 until you read off that entire report which
13 doesn't sound very positive.

14 CO-CHAIR MONSON: So --

15 DR. ROILAND: So, in the initial round
16 of evaluation, there were some concerns around
17 the testing of the measure, I think, particularly
18 in terms of they had a lot of subgroups, they had
19 a larger sample, but a lot of subgroups that they
20 tested the measure on.

21 And, so, the Committee asked the
22 developer to bring back additional testing which

1 they did during the post comment call which
2 happens after the draft report is released.

3 With that information, the Committee
4 was satisfied that the measure met reliability
5 and validity and also demonstrated performance
6 gaps.

7 MS. JUNG: Yes, and the following five
8 paragraphs, it got a lot better.

9 MS. ROILAND: So, ultimately, it was
10 endorsed this past October as I believe Kerry
11 mentioned.

12 CO-CHAIR MONSON: Joan?

13 MEMBER ZLOTNIK: My concern is really
14 on the workforce issues. They -- without knowing
15 how the survey is used and then how the
16 information is then reported, it has the
17 potential for giving -- providing very unclear
18 information.

19 So, like, in general, like, the
20 information that's included in those 19 areas
21 that have been obviously functionally put
22 together, makes sense. But, it just concerns me

1 that the surveyors are using words for staff that
2 multiple meanings.

3 And, while someone can be filling it
4 out, I just feel like I'd be sitting in some
5 congressional hearing and, you know, someone
6 would say, oh well, these, you know, case
7 managers aren't doing their job or whatever it
8 is. These things happen.

9 So, that's my concern.

10 CO-CHAIR MONSON: Yes, D.E.B.?

11 MEMBER POTTER: In the interest of
12 disclosure, I'll say I've served on the Technical
13 Expert Panel for this survey for many years.

14 What we didn't see the full scope of
15 was all of the up front questions. You know, it
16 starts with a program. Does someone come in to
17 your house and who do you call them?

18 And, because it's a CAPI and a CATI
19 survey, the interviewer can insert the
20 respondent's concept of what that is. Oh, Mary
21 helps me make my bed and get dressed in the
22 morning.

1 And, so, the subsequent questions say,
2 and does Mary do this and does Mary do that?

3 That's one of the advantages of having
4 it be a CAPI or a CATI survey to try and deal
5 with all of those legitimate issues that you
6 bring up.

7 And, as we heard earlier, in some
8 states there are multiple versions of this. But,
9 because the accountable entity is a program, it's
10 not like everybody in a state. You start with,
11 well, what does the program call it? You know,
12 and builds from there.

13 I don't know if that helps but --

14 CO-CHAIR MONSON: Wendy?

15 MEMBER FOX-GRAGE: I am all for this.

16 We are so in need of an experience of care for
17 people in home and community based services
18 programs. So, I'm a fan.

19 My only question is this, and it's
20 because I'm new, but I don't know this, and
21 that's the question of, you know, being in the
22 family versus the -- and also being in the

1 starter set.

2 So, I just want to make sure, then, in
3 the family, do we have any -- I know we've spent
4 all day yesterday voting on measures that were
5 really more for an institutional setting.

6 So, I just wanted to ask what that --
7 the part that we didn't cover which is the whole
8 family of services, is there anything else at all
9 that's experience of care survey on HCBS? There
10 isn't, is there? Okay, that decides it for me.

11 CO-CHAIR MONSON: Clarke?

12 MEMBER ROSS: So, right, Wendy. So,
13 this is a priority of the Disability and Aging
14 Collaborative because we don't have these
15 measures.

16 This is tested in eight states and
17 this is already endorsed. And, I'm concerned
18 that we would send a message to the entire field,
19 not just National Quality Forum, that, because
20 the status of social workers and, as they say on
21 The Hill, my good friend Joan and I've worked
22 with Joan since the 1980s on nursing home reform,

1 right.

2 Because the social work phrasing isn't
3 clear, we're going to vote down one of the few
4 beneficiary experiences in home and community
5 based services which we're all about.

6 And, the point I was going to make to
7 Stacey on the side in response to Pam's question
8 was, I asked at the MMCO stakeholders meeting we
9 had two weeks, this very question, what is the
10 use by MMCO and the duals demos?

11 And, Tim said there's a question on
12 how to best fit it. And I went to Steve Kaye,
13 who's one of the five researchers at the
14 University of Minnesota. He directs the
15 University of California San Francisco Center and
16 was co-chair of the National Quality Forum HCBS
17 Committee.

18 And, he provided data on three states
19 that show a significant number of the dual demo
20 participants are also recipients of home and
21 community based services under Medicaid.

22 So, I'm just getting really uneasy

1 that, because every one of these things has
2 technical challenges, but I'm concerned about the
3 big message.

4 And, the message should be, this is
5 needed. It's well overdue, it's important and it
6 should part of not only the duals family, but
7 personally, it's so important, it should be part
8 of the starter set.

9 So, that's all I can do to plead with.

10 MEMBER PARKER: And, I just want to
11 echo what Clarke is saying. I think, with all
12 its flaws and CAHPS surveys, you know, have lots
13 of flaws in them, it's the best thing that I've
14 seen and it moves it forward with some of these
15 other little accouterments that I've already
16 talked to you about.

17 And, I think with the advocacy
18 community being where it is and we just heard
19 that from two of them, I think it would be -- I
20 would feel really bad if this was my first and
21 last meeting of this group and I had been part of
22 putting something like this to death when it's an

1 opportunity to make such a big movement forward.

2 So, I would just plead for everybody
3 to support it.

4 CO-CHAIR MONSON: Alison and then Tom?

5 MEMBER CUELLAR: Yes, I'd like to say
6 I wholeheartedly agree. It's so difficult to try
7 to evaluate these dual demonstrations without an
8 instrument like this or managed LTSS that it's --

9 When we were looking at this thing, it
10 was still over 60 minutes long. It hadn't been
11 tested and so there was nothing the state could
12 do or that we could help the state with at that
13 point.

14 But, we made something up. This is a
15 huge improvement.

16 MEMBER LUTZOW: Yes, I'm in favor,
17 too, only because we need another CAHPS survey to
18 debate over for the -- in the future.

19 But, I mean, this is a case where, you
20 know, we can't let the perfect get in the way of
21 the good.

22 You know, in Wisconsin right now,

1 every MCO is doing its own survey as opposed to
2 using a standard survey. And so, there's no way
3 to, in terms of these community based services,
4 there's no way to compare one MCO to the other.

5 We send in our survey and they record
6 the results and our survey isn't like anybody
7 else's.

8 And, so, I mean it's clear the field
9 needs this. It's looking for it and, you know,
10 it can get perfect over time.

11 CO-CHAIR MONSON: So I would just add
12 that from another -- from a national health plan
13 perspective we would love this. Look, at the end
14 of the day all of us are here to help the
15 individuals who are duals, in this case people
16 with HCBC services, live the best life possible
17 and remain in the community. And this is a
18 critical tool for us to be able to make sure
19 we're doing that correctly.

20 And if we can't -- if we as a
21 committee can't get this one over the -- this is
22 a very well-developed measure, by the way. I've

1 been following this one for years. This one has
2 gone under a lot of scrutiny. There's been a --
3 and there's also been a lot of sharing of
4 information along the way, so it's not been
5 hidden. It's very well designed. It's been
6 executed well. If we can't push this one over,
7 then we do deserve to be put on hiatus.

8 Okay. Are we ready to vote? Are we
9 -- Madison, are we doing your thing or we're
10 doing it by hand?

11 DR. ROILAND: And, Alice, if you're
12 still on the line, you can chat your vote to us
13 in the webinar platform chat box.

14 MEMBER LIND: Okay. Got it.

15 DR. ROILAND: Thank you.

16 CO-CHAIR MONSON: Okay. Did we say --
17 I'm sorry. Are we using the clickers? We have.
18 Okay. All in favor?

19 PARTICIPANT: Wait, wait.

20 CO-CHAIR MONSON: Oh, sorry. I think
21 we start with the family. We're doing the family
22 first and then we'll do the --

1 (Simultaneous speaking.)

2 MS. JUNG: So voting for Measure 2967,
3 CAHPS home and community-based services measures,
4 is now open for the addition to the family.
5 Well, okay. So we'll start off with yes. So
6 raise your hand if you would indicate yes?

7 (Voting.)

8 MS. JUNG: And she's yes.

9 MS. BUCHANAN: Oh, she's yes?

10 MS. JUNG: Yes.

11 MS. BUCHANAN: Okay. Great. So we
12 have 15 in favor. So that's -- okay. And so
13 there would be zero not in favor. So it passes.

14 MS. JUNG: It passes? Okay. So
15 Measure 2967 passes with 100 percent for addition
16 to the family of measures.

17 The next vote will be the vote for
18 addition to the starter set. Please raise your
19 hand if you would like to vote yes for that.

20 CO-CHAIR MONSON: Yes, hold on just
21 one second. Jen has a quick question.

22 MEMBER RAMONA: Sorry, being newbie-

1 ish. Can you define what the starter set -- what
2 that really means for the use of it? Sorry.

3 CO-CHAIR MONSON: So the starter set
4 is supposed to be that if a state or an entity
5 wanted to pull -- what are the first measures
6 they would use to do dual measures? And this
7 would be in that -- as opposed to a large group
8 of measures. This is the first ones you'd pull
9 out. So there's 10, 15 on the starter set right
10 now?

11 PARTICIPANT: Seven.

12 CO-CHAIR MONSON: Seven? I wasn't
13 that -- high priority is the way I think about
14 it. These are high priority measures.

15 MS. JUNG: Okay. So voting for the
16 starter set of Measure 2967, CAHPS home and
17 community-based services measures is now open.
18 Please raise your hand if you would like to
19 indicate yes.

20 (Voting.)

21 MS. BUCHANAN: So I have 14 in the
22 room. So, Alice, yes. We have 15 yeses.

1 MS. JUNG: So with 15 yeses that's 100
2 percent and the measure is now added to the
3 starter set.

4 CO-CHAIR MONSON: Awesome. Well done.
5 We have -- no, in fairness, that's very true. We
6 have accomplished something. I mean, this is
7 important, because now that it's NQF-certified,
8 this also means that as -- if you think about
9 from -- I'll take my parochial view with managed
10 care -- and we know many states are moving to
11 MLTSS. They need to have ratings. They have to
12 have a quality rating system by -- because of the
13 new managed care rule. So now this will be one
14 that they can use because this is an endorsed
15 measure, which is great.

16 Okay. We're doing the strategic --
17 yes, all right. So this is our -- this was -- as
18 you will recall from yesterday, this was -- we
19 said we'd have reserved time at the end of today
20 again to provide more thoughts back to CMS for
21 final parting thoughts about dual measures. So I
22 will open it up to the group in terms of those

1 final thoughts. Anything that we really want to
2 -- and I would say things that you want to leave
3 CMS with: recommendations, ideas, this is your
4 forum to do that.

5 (Pause.)

6 CO-CHAIR MONSON: And you're not
7 allowed to leave yet.

8 (Laughter.)

9 CO-CHAIR MONSON: Yes, and it may be
10 that -- Alice, you -- we have not given you an
11 opportunity to speak. Is there anything else
12 that you want to share? And you weren't -- you
13 didn't join the conversation yesterday.

14 MEMBER LIND: I'm trying to think if
15 I remember the topics from yesterday, if I would
16 have had something unique. But I'm really
17 comforted with the compilation of new folks that
18 have been added to the work group and don't feel
19 that I have anything that my colleagues wouldn't
20 have said yesterday.

21 CO-CHAIR MONSON: Tom?

22 MEMBER LUTZOW: Yes, I think as a

1 general statement from my perspective I would
2 never want to go back. I would never want to go
3 back to 10 years ago. I think, yes, we can
4 debate this and nitpick that and -- but what's
5 been achieved in terms of performance measures
6 and getting people on the same page and working
7 with evidence-based outcomes and that sort of
8 thing, this is quite amazing. This is quite
9 amazing. And the short amount of time that it's
10 taken to get here.

11 Now I still want to debate. It's
12 about adrenaline and it's about living longer.
13 And certainly we can nitpick, but life without
14 measures, I don't want to go back. Now I want to
15 debate which ones should apply and how they
16 should be weighted and all of that, but something
17 great has happened here, not just in this room,
18 but within the total healthcare environment.

19 MEMBER AGUIAR LYNCH: So I just have
20 a -- sort of a plea for you guys at the Duals
21 Office. So I know you guys are focusing on
22 filling in the measurement gaps and working on

1 social risk factors and the Star Ratings program.
2 And as you guys are working on developing your
3 Star Rating system for the MMPs, I think this is
4 such an amazing opportunity for you all. And I
5 think you guys are the office that's perfectly
6 positioned to be able to do it, to think outside
7 of the box as much as you can to really pull in
8 what you've been hearing from this workgroup over
9 so many years and to try to get the measures that
10 are actually accurate and then the way that the
11 system is developed in a way that's -- truly is
12 measuring quality and comparing quality
13 accurately and that it has the right incentives
14 for in this instance plans as they move forward,
15 and not to repeat the mistakes that were made in
16 the original Star Rating system. So I know it's
17 a tall order, but you guys could do it.

18 MEMBER LYTLE: Can I respond?

19 CO-CHAIR MONSON: Yes, of course.

20 MEMBER LYTLE: Just in response to
21 both, I think we totally agree we don't want to
22 go backwards either. It's not -- it's not our

1 desire, our goal, our hope or our strategy. So
2 we are in complete agreement. As it concerns the
3 Star Rating system, I think that you're right.
4 And we're trying to be very thoughtful about it
5 because the current Star Rating system isn't
6 really applicable for the population that we
7 serve. It's what we have, but we recognize that
8 we need something that works better.

9 And so hopefully -- unfortunately I am
10 drawing a blank as to where we are in the
11 process, but I know that throughout the process
12 we've done public comment and we've tried to get
13 input. And so I would hope that this -- the
14 members of this group will continue to be engaged
15 in that way because your feedback is still very
16 important to us, not just with the Star Rating
17 system, but in everything we do. We do try to
18 incorporate the voices of those persons who we
19 serve, whether they be the people who are
20 receiving services or the people who are
21 administering them. And so we just hope to
22 continue to hear from you from that perspective.

1 So we're trying.

2 CO-CHAIR MONSON: Yes, ma'am?

3 MEMBER PARKER: Of course my
4 everlasting plea to CMS is that as you look at
5 the MMP ratings system that you've solicited
6 comment on and everything, that we look at what
7 is applicable to the integrated D-SNPs,
8 recognizing that that's a larger even platform
9 than the MMPs and has many of the same features
10 and that we're moving -- trying to move that
11 world further and further toward something that
12 can come together in terms of what the MMPs and
13 the D-SNPs are both accomplishing, both working
14 on the same stuff.

15 And that population also, especially
16 for the integrated ones, of course is heavily
17 dominated by the home and community-based group
18 as well. So just what's good for one should be
19 brought over to the other, and that's -- we talk
20 about that in terms of network materials and
21 network approaches, and also measurement.

22 And then as we're thinking about that,

1 especially on behalf of the D-SNPs, we have to
2 think of how many layers are they under. Are
3 they under a whole set of things from the state
4 level, another whole set from Medicare, and then
5 yet another set that's specific to duals and how
6 do we make all that make more sense? And as you
7 work that out for the MMPs I think it's going to
8 be very instructive to then see how that could
9 apply to the D-SNP world and get rid of some of
10 those layers by looking at what you're doing with
11 MMPs. So that's just my own --

12 (Simultaneous speaking.)

13 MEMBER LYTTLE: We hope so. We've
14 spent a lot of days thinking about how to make
15 things applicable across --

16 MEMBER PARKER: Right.

17 MEMBER LYTTLE: -- all of the care plan
18 models. And our hope and desire is that whatever
19 we do with the MMPs is instructive and then
20 applicable across populations with nuances of
21 course, because the way they serve and the way
22 they contract are different. But Pam knows all

1 too well some of the concerns and constraints
2 we've had there, but we still press.

3 MEMBER PARKER: Yes. And then we have
4 to think of the providers, because they might be
5 working under fee-for-service systems as well as
6 all these other layers. And so we have to make
7 it somehow make sense because they can't be
8 expected to do everything that a thousand
9 entities are telling them to do. They've got --
10 we've got to focus it so that it makes sense at
11 that level, too.

12 MEMBER LYTTLE: And can I just note one
13 more thing? I know I have probably talked a lot
14 about the fact that we have demonstrations and we
15 have things happening, but I also want to be very
16 clear that that's part of what we do. And so we
17 are very concerned with how D-SNPs and fee-for-
18 service providers and all other dual-eligible
19 individuals who are not in plans are receiving
20 care. So I just wanted to emphasize that because
21 I know I've sort of referenced it as our
22 approach, but it's -- our office's goal is not

1 just about demonstrations. It's about the
2 population at large.

3 MEMBER PARKER: And we wish you
4 well --

5 (Laughter.)

6 MEMBER PARKER: -- as they're -- I
7 mean, it's so wonderful to have you all and to
8 have a focus point that we can even have a
9 discussion about this. I know somebody's
10 supposed to be kind of monitoring it, but that
11 wasn't always the case for the 20, 30 years
12 before. And we're just hoping it all continues
13 and we'll be watching for --

14 CO-CHAIR MONSON: So I would add one
15 thing for you to think about, which would be I
16 think getting to a common assessment form is a
17 highly unlikely endeavor. I would wish it to be
18 true, right, across -- for all duals, however, I
19 do think what is achievable is the idea of some
20 common -- a handful of common questions as
21 opposed to a whole common assessment, but a
22 handful of common questions could be driven by

1 measurement, right, that the measures require
2 certain questions, especially around ADLs and
3 IADLs.

4 If we had a common way of measuring
5 them, will that allow us to risk-adjust better,
6 both from a financial perspective and also from a
7 quality perspective. So I would highly encourage
8 you all to think about where you could place some
9 small bets from -- and do it from the Medicare
10 side that would apply to all eligibles.

11 Tom?

12 MEMBER LYTTLE: I think that makes
13 sense. And I just want to say if I'm not looking
14 at you, I'm typing, because if I don't write it
15 down, I might not remember it. Sorry about that.

16 MEMBER LUTZOW: Yes, I think when you
17 look at how this field is organized now with
18 respect to measures, not just a common -- we
19 don't need just a common set of questions. We
20 need a common set of measures across the entire
21 system. And it is sort of striking that that's
22 not really prominent.

1 The value of the IMPACT Act is it is
2 going to test what happens when nursing homes,
3 home health agencies, hospitals and others get --
4 rally around a common measure like readmission
5 prevention. And we're going to be able to tell
6 whether joining all those resources at the hip
7 around a common measure really can make a
8 difference. But I think there's other things
9 within the family of measures that we now have,
10 like diabetes, where if it were a measure that
11 everybody had to subscribe to we would see
12 population health gains that we don't now see.

13 So why we're resistant to this as an
14 industry: government side, provider side,
15 whatever side you want to consider, why that
16 isn't sort of self-evident as a value I haven't
17 been able to figure out, but it seems so clear
18 that if we want traction, we're all going to have
19 to get behind the same measure and push.

20 CO-CHAIR MONSON: Other thoughts?

21 MEMBER LIND: Hi, this is Alice. Can
22 I actually insert something after all?

1 CO-CHAIR MONSON: Oh, I don't know.

2 (Laughter.)

3 CO-CHAIR MONSON: Okay. Go ahead.

4 MEMBER LIND: So just the conversation
5 about where our attention is focused and who has
6 still kind of been the left-unattended-to group,
7 the population that is the most complicated for
8 me personally as a state bureaucrat right now are
9 the folks who are dual-eligible with behavioral
10 health needs.

11 We are using integrated managed care
12 to cover 80 to 90 percent of the folks in a
13 completely integrated package of medical and
14 behavioral health services, and the duals are the
15 ones that really are still in this kind of
16 bifurcated model where the Medicare and the
17 Medicaid benefits around behavioral health are
18 really so different. And the providers have been
19 just kind of cobbling together benefits for these
20 clients as best as they can, and our inserting
21 the managed care plan really has not helped this
22 situation at all, just for those duals.

1 And so I'm really resonating with that
2 thought about the folks who are not in the
3 demonstrations are the ones we really are going
4 to have to pay attention to, and for us right now
5 it's the folks with behavioral health needs.

6 CO-CHAIR MONSON: Yes, Charlie?

7 MEMBER LAKIN: Well, we could go
8 through this. We've focused on the dependent
9 variables. We could spend just as long talking
10 about the independent variables. And I think
11 those are discussions that are really important
12 as we move to some consensus that we might be
13 able to measure outcomes for people in the same
14 way despite very different characteristics. And
15 that becomes increasingly important I think when
16 we talk this way.

17 I'm struck having worked mostly in the
18 area of intellectual disability how we have never
19 come up with a better predictor of outcomes for
20 people than their level of intellectual
21 disability. And so often we just -- we're
22 satisfied with saying they have an intellectual

1 disability. That is really meaningless.

2 So at some point we really do need to
3 think about the independent variables that really
4 are important. And I just think it's going to be
5 increasingly important as we develop data systems
6 that encompass just more and more of these fields
7 that have lived in silos, need to try and get out
8 of their silos. But the characteristics of people
9 in a broadly framed disability community are
10 hugely different and we need to accompany our
11 consensus around the dependent variables with
12 some consensus about the independent variables, I
13 think.

14 CO-CHAIR MONSON: All right. Well, I
15 think that brings us to a close. I think it's
16 important for us to first of all thank CMS for --
17 oh, did you want to --

18 MEMBER LYTTLE: I just wanted to say
19 thank you. Should I do that now?

20 CO-CHAIR MONSON: No, I was trying to
21 say thank you first.

22 (Laughter.)

1 MEMBER LYTTLE: It's not fair.

2 (Laughter.)

3 CO-CHAIR MONSON: Go ahead.

4 MEMBER LYTTLE: Well, I get to go
5 first. Thank you very much.

6 But I do want to thank the group again
7 for all your hard work over the years. I think
8 that many of the strides that we've made as an
9 office and an agency are in large part of your
10 contributions, and that -- we can't say that
11 enough. Even though I think some people said
12 this is their first meeting and they're new, that
13 is -- I know that feeling. And it's still
14 valuable because your work in the industry stands
15 for itself and still contributes to the ongoing
16 discussion about people who are Medicare and
17 Medicaid-eligible. And so we appreciate you and
18 we appreciate NQF for your work with the
19 workgroup over the years.

20 We aren't all happy and excited about
21 where we are right now in terms of not being able
22 to see you in a meeting again, but we are excited

1 about the way the work is going to continue to
2 move forward, and hopefully we'll be able to have
3 these discussions again in another forum not too
4 long from now.

5 CO-CHAIR MONSON: And I was just
6 reminded we need to do public comment.

7 DR. ROILAND: Hi, Shawn. If you
8 wouldn't mind opening up the lines for public
9 comment?

10 OPERATOR: Okay. At this time if
11 you'd like to make a comment, please press star
12 then the number one.

13 (Pause.)

14 OPERATOR: And there are no public
15 comments at this time.

16 DR. ROILAND: Thank you.

17 CO-CHAIR MONSON: So I do think we
18 should thank CMS, because I think it was very
19 forward-looking to put this entire infrastructure
20 together and then to call out the duals in
21 particular and allow this group to do its work.
22 And that's no small measure to Stacey and all her

1 colleagues, because we do know that the MMCO is a
2 true partner and collaborator in improving the
3 care and the lives of all dual-eligibles
4 regardless of their payer source. So thank you
5 for that.

6 I think we should thank the NQF staff
7 who do so much work.

8 (Applause.)

9 CO-CHAIR MONSON: And it's kind of
10 unbelievable, and we couldn't have done any of
11 this without them. And I think that we have left
12 ourselves -- while we are going on hiatus, we
13 have left ourselves I think with a very good
14 family of measures and a great starter set,
15 especially with the addition of the CAHPS
16 surveys. And so I think if part of our purpose
17 is to make the world a little bit of a better
18 place, then we've accomplished that.

19 And thank you, everybody. Most of you
20 have been on this longer than I have, so thank
21 you to everyone who was doing this before some of
22 us newbies got on here, but it's been a pleasure

1 working with everybody and hopefully we will have
2 another opportunity to convene under a different
3 banner.

4 So I think we are adjourned.

5 MS. JUNG: We need to --

6 CO-CHAIR MONSON: No? No.

7 (Simultaneous speaking.)

8 MS. JUNG: -- next steps. And we have
9 just --

10 (Laughter.)

11 MS. JUNG: We just don't want to let
12 you guys go, yes. Just a few closing
13 housekeeping things.

14 So in terms of -- we have taken
15 copious notes and have noted all of your concerns
16 and everything, and those will be summarized in
17 our -- in the report that will be finalized in
18 August, but before it is finalized it will go out
19 for a 30-day public comment period. That will be
20 from June to July.

21 There is our contact information. And
22 you guys have the slide deck that was also

1 emailed to you. The project page is linked here
2 as well as the Committee SharePoint page with the
3 slides, family of measures, duals, Excel, agenda.
4 All the meeting materials from today will be
5 posted. And you will be receiving a very long
6 email of the laundry list of resources and
7 follow-up items that you have all requested.

8 Listed also here is the project staff
9 contact information. There's our inbox, which
10 I'm sure you've received many emails from and the
11 individual emails from our staff team.

12 And we thank you for your patience
13 with all the technical difficulties and
14 everything, the clickers, and really appreciate
15 your work. And turning it over to Debjani for a
16 few closing remarks.

17 MS. MUKHERJEE: So again, I would like
18 to thank all of you, the longstanding and sort of
19 the new members, and especially Michael for sort
20 of shepherding us to the bittersweet end and sort
21 of stepping in. For any workgroup committee to
22 work really well, it's a lot on the chairs to

1 sort of manage and sort of keep up with the flow
2 and sort of manage the flow.

3 So thank you to the NQF staff, the
4 team, the duals team. I think a lot -- as you
5 can imagine, a lot of work has gone into this and
6 with the news a lot of sort of rejiggering the
7 different sort of aspects of the presentations
8 and things and that were all sort of done last
9 minute. So it takes a lot sort of from everybody
10 to sort of rally together and hope -- and to CMS
11 for allowing us to work with them for this long
12 and sort of in this capacity. I think it's been
13 very interesting.

14 And with that, I want to sort of wish
15 everybody a safe journey, safe travels. Clarke,
16 with his surgery and being in recovery coming
17 here, thank you.

18 And so with that, I think we're
19 officially adjourned.

20 (Whereupon, the above-entitled matter
21 went off the record at 4:13 p.m.)
22

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